PATIENT PERSPECTIVES OF THE IMPACT AND LONG-TERM MANAGEMENT OF LYMPHOEDEMA

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Abstract

Lymphoedema is a chronic and incurable condition. It is characterised by impaired drainage of lymphatic fluid, resulting in excess accumulation of fluid, and can affect all regions of the body. The physical symptoms of lymphoedema vary, but can include swelling, heaviness, tightness, numbness and pain, among others. When severe, these symptoms can be debilitating and significantly impact on employment, social functioning, psychological wellbeing, and on a person's ability to perform daily activities. Without treatment, the condition can progress and there is risk of serious complications, including infection. In Australia and other developed countries, lymphoedema most commonly develops following cancer treatment. Given the high number of people expected to develop lymphoedema each year and the widespread impacts on quality of life, the public health implications are clear.

The primary aim of this PhD research was to consider the patient's experience of lymphoedema and associated treatments, and how this influences long-term management of the condition. In doing so, there were three components to this work. As the majority of the research exploring the impact of lymphoedema on quality of life has been conducted with women with breast cancer-related lymphoedema, the first component of this PhD research was to further understanding of the impact of lower-limb lymphoedema (LLL). The focussed review of the literature (subsequently published and included in Chapter 2 of this thesis) explored the impact of LLL on quality of life following gynaecological cancers. The review confirmed that many of the challenges faced by those with ULL are shared by those with LLL. Additional concerns of those with LLL included exacerbations of symptoms when required to sit or stand for long periods of time, increased concerns about sexuality and intimacy, difficulties finding appropriate footwear, and trouble performing self-care aspects of treatment.

The second component of this PhD work aimed to describe the use of different treatment types by people with lymphoedema. Secondary data analysis from a study focusing on the use of complementary and alternative medicine (CAM) found that

people with lymphoedema used a wide range of complementary therapies to manage their symptoms. Interestingly, when rating the effectiveness of treatments, both CAM and mainstream treatments were considered to be effective (mean±SD: 5.2±1.6 and 5.3±1.5, respectively, on a 7-point Likert scale). Despite the high perceived effectiveness of mainstream treatments, many people were using multiple treatments concurrently, and almost half (45%) had also used one of 22 CAM treatments. It is plausible that people with lymphoedema use a combination of treatments in order to manage different symptoms of lymphoedema. The effectiveness of different treatments for improving specific symptoms and patients' reasons for continued use of multiple treatments were considered further in the final component of this work.

The third component of this research involved the design and conduct of a cross-sectional study to investigate the use of a range of treatments by people with lymphoedema, as well as the factors influencing ongoing treatment use. While intervention studies have provided information about the effect of treatments on reducing limb volume, little attention has been given to treatment effect on lymphoedema-related symptoms, or the burden of long-term treatment on patients. Non-adherence to treatment is considered to be the most important modifiable factor compromising treatment effectiveness for chronic conditions. The World Health Organisation adopts a five-dimensional approach to explaining the factors influencing treatment adherence; specifically, health care system factors, social and economic factors, treatment-related factors, condition-related factors and patient-related factors. A primary objective of this cross-sectional study was to examine the relationship between these factors and use of lymphoedema treatment(s).

The self-administered questionnaire developed for this study, was completed by 421 eligible participants; adults aged 18-91 years diagnosed with primary or secondary lymphoedema, living in Queensland, New South Wales or Victoria. Similar proportions of participants had ULL (46%) and LLL (44%), while 10% had symptoms affecting multiple regions of the body. The questionnaire was used to collect information about a range of social and economic characteristics, lymphoedema characteristics, partcipants' use, perceived effectiveness and acceptability of treatments, and reasons for ceasing treatment use. The study focussed on the most commonly prescribed mainstream treatments: compression garments,

self-administered massage, manual lymphatic drainage (MLD), prescribed exercises, complex physical therapy (CPT), compression bandaging, pneumatic compression pumps, laser therapy and surgery. In addition, open-ended questions allowed participants to provide information about additional treatments they had used. Descriptive analyses were used to examine and present the range of treatments used, as well as the acceptability and effectiveness of treatments. Bivariate analyses stratified by lymphoedema location were used to investigate subgroup differences in treatment use between those with upper- versus lower-limb lymphoedema. Multivariable logistic regression analyses were conducted to explore the complex relationships between healthcare team and system factors, social and economic, treatment-, condition- and patient-related factors, and lymphoedema treatment use.

The majority of people with lymphoedema had used multiple treatments to manage their symptoms, with compression garments (86%), self-administered massage (79%), prescribed exercises (69%) and MLD (67%) used most commonly. Over half (62%) of all participants had used more than four treatment types, while 5% had used only one type of treatment. Patients' continued use of treatment (considered an indicator of long-term use) varied widely across treatment types. For example, less than half of those who had used laser, CPT and/or bandaging reported continued use (43%, 32%, 30%, respectively), whereas 79%of participants who had ever used compression garments were currently using them. Participants reported experiencing improvements in swelling, heaviness and tightness following treatment, irrespective of the type of treatment. Across the range of lymphoedema-associated symptoms, compression garments, CPT, compression bandaging and MLD were reported as effective by higher proportions of participants than other treatments (40-60% reporting symptom improvements, compared with <30% reporting improvements in symptoms following exercises and self-massage).

The cost, time and discomfort associated with treatment were considered unacceptable by a significant proportion of people with lymphoedema, and these factors represented common reasons for stopping treatment. For example, over half of the participants who used compression garments found the cost unacceptable. The time involved with treatment was most significant for intensive treatments (CPT, compression pumps and compression bandaging) and was reported as unacceptable

by 20-27% of participants. Around one in three people who had used compression bandaging (36%) and garments (31%) found the discomfort unacceptable. Also, between 26-36% stopped using CPT, compression garments, laser therapy or MLD because the treatment was too expensive, while 23-40% cited the effort involved as the reason they stopped using prescribed exercises, compression garments and bandaging, and self-massage. The time involved was a reason for ceasing use of self-massage, prescribed exercises, MLD and CPT, for between 23-40% of those no longer using each treatment. Of note, these findings were consistent irrespective of sociodemographic characteristics.

Results from adjusted multivariable analyses supported the hypothesis that continued use of treatment was associated with patient-reported acceptability and effectiveness. Acceptability of time and discomfort involved with undertaking treatment was associated ($p<0.05$) with continued use. That is, odds of continued use of MLD, compression garments, bandaging, self-massage and CPT was 2+ times higher for those who found the time and discomfort acceptable, compared with those who found time and discomfort unacceptable. Further, those who perceived the treatment as being effective at improving LE and its associated symptoms had higher odds (2+, $p<0.05$) of continued treatment use than those who did not perceive the same level of benefit for compression garments, self-administered massage, prescribed exercises and MLD.

Previous research has found CPT, compression garments and bandaging contribute to significant volume reductions, and the current study has confirmed that these treatments are also perceived by patients to be effective for improving a range of other lymphoedema symptoms. However, this research shows that the cost and discomfort associated with these treatments were considered unacceptable to significant numbers of participants. Further, the effort involved and difficulties accessing treatment were raised by participants as additional reasons for discontinuing treatment. These are important considerations for health professionals supporting patients with long-term lymphoedema management.

When research findings suggest particular treatments improve symptoms and complex treatment programs are prescribed, it is essential to consider the burden of treatment and the ability of patients to overcome treatment barriers, in order to

maximise treatment success. This study was the first to focus on the patient's perspective of lymphoedema treatment effectiveness and acceptability. Physical responses to treatment are likely to vary between individuals, and the availability and accessibility of treatment differ according to patient-related factors (e.g., affordability of compression garments and MLD) and health-care system factors (e.g., adequately trained health professionals in regional areas). In addition, people may have difficulty performing self-management activities, and do not always have a support person available to assist long-term. It is necessary for health professionals to consider all of these factors to ensure appropriate treatment prescriptions are made. Future research is needed to determine the most effective and feasible treatment options for all aspects of this chronic condition. This research has shown that improvements in physical symptoms, function, mobility and visual appearance are important to the majority of people with lymphoedema, highlighting the need to consider these outcomes as additional measures of treatment effect in future efficacy and effectiveness research. Considering long-term treatment is required to prevent progression of lymphoedema and complications, it is important to consider the commitment required by patients and minimise the impact of the cost, time, effort and discomfort associated with treatment.

Table of Contents

List of Figures

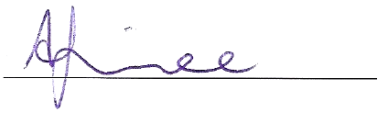
List of Tables

List of Abbreviations

CAM	Complementary and alternative medicine
BCRL	Breast cancer-related lymphoedema
QoL	Quality of life
ULL	Upper limb lymphoedema
LLL	Lower limb lymphoedema
CPT	Complex physical therapy
MLD	Manual lymphatic drainage
RCT	Randomised controlled trials
CDT	Complex decongestive physiotherapy
SLD	Simple lymphatic drainage
LLLT	Low level laser therapy
PCP	Pneumatic compression pumps
LVA	Lymphaticovenular anastomosis
HBM	Health Belief Model
TRA	Theory of Reasoned Action
TPB	Theory of Planned Behaviour
TTM	Transtheoretical model
WHO	World Health Organisation
LAV	Lymphoedema Association of Victoria
SPSS	Statistical Package for the Social Sciences
ISL	International Society of Lymphology
LAQ	Lymphoedema Association of Queensland
OR	Odds ratio
PHI	Private health insurance

Statement of Original Authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Signature: 

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Chapter 1: Introduction

1.1 BACKGROUND

Lymphoedema is a chronic condition that can have a significant impact on quality of life. In Australia, and other developed countries, cancer treatment is the most common cause of lymphoedema [1]. Although advances in cancer diagnosis and treatment have led to increased survival rates, a cancer diagnosis can have long lasting effects on patients. Current estimates suggest more than 8,000 patients are expected to develop secondary lymphoedema following cancer in Australia each year [2]. Lymphoedema is reported to be among the most serious and feared sequelae of cancer treatment [3–5], with some patients describing living with secondary lymphoedema as more distressing than their original cancer diagnosis [6].

Over the past 50 years, considerable research has been done in the area of lymphoedema treatment. This has led to greater understanding and change of practice in some areas of lymphoedema management (e.g., patients are now often advised to use the affected limb in daily activities and exercise, compared to past advice to avoid exercise) [7,8]. However, the quality of the research comparing the efficacy and effectiveness of various prevention and treatment options has been variable.

The majority of lymphoedema treatment studies investigated whether treatments can reduce the degree of swelling, often measured by limb volume. Measurements of limb volume before and after treatment provide an objective measure of improvement, as well as enabling comparisons between treatment types. These are important qualities of outcome measures in intervention studies. However, less attention has been paid to the other common impacts of lymphoedema, including associated symptoms, loss of function, reductions in physical or emotional wellbeing and changes in appearance, and to whether treatments have any effects on these.

The purpose of this research was to investigate the impacts associated with lymphoedema that are important to patients, and how these relate to treatment use and effectiveness. While previous research has focused on determining which

treatments yield the greatest limb volume reductions, this may have limited value in the translation of research into best practice. It was hypothesised that patients' perceptions of treatment effectiveness, and the barriers they face in continuing long-term treatment, are likely to play a significant role in the success of lymphoedema treatment.

1.2 SCOPE OF THIS RESEARCH

This PhD program of work focussed on adults (over 18 years) with lymphoedema and did not include children or adolescents. The burden of treatment for children with lymphoedema would impact on both the child and their parent (or other adult carer) and would need to be investigated separately. This research had three components: (1) a literature review of the quality of life of people with lower-limb lymphoedema (LLL) following gynaecological cancers [9]; (2) secondary data analysis evaluating the use of complementary and alternative medicine (CAM) by people with lymphoedema [10], and; (3) the development, conduct and evaluation of a cross-sectional study exploring the use, acceptability and perceived effectiveness of lymphoedema treatment. The latter cross-sectional study included patients with both primary and secondary lymphoedema, since treatment is the same irrespective of lymphoedema type. While some characteristics of lymphoedema may vary between the two groups, for example duration and severity, these possible differences were considered to be of interest in this study. Those with secondary lymphoedema following any type of cancer were included. The majority of lymphoedema-related studies have involved patients with breast cancer-related lymphoedema (BCRL) only, limiting the generalisability of research findings beyond breast cancer cohorts. This research gap was addressed by the first component of this research, which was a review of the literature on the quality of life of those who developed LLL following gynaecological cancers, and the cross-sectional study, by including patients who had been treated for any type of cancer.

The cross-sectional study aimed to explore patients' experiences of a range of treatment types. Mainstream treatments include compression bandaging, garments and pumps, manual lymphatic drainage (MLD), laser therapy and exercise. Surgery is generally only prescribed for those who do not respond to more conservative

treatment. These treatments are most commonly prescribed by health professionals, and are the focus of the majority of lymphoedema treatment research. While it is recognised that the prescription and use of CAM is increasing [11], these treatments have been given little research attention. The second component of this study, a report of the use of CAM by women with lymphoedema following breast and gynaecological cancers, aimed to provide an initial overview of the use of CAM by this patient group. While the cross-sectional study focussed on mainstream treatments, it also allowed patients to provide information about their use of other treatments including CAM.

1.3 THESIS OUTLINE

The details of this research program are divided into chapters, as follows: Chapter 2 provides a comprehensive literature review of the research into lymphoedema management and concludes with a conceptual summary illustrating the issues potentially influencing lymphoedema treatment adherence and effectiveness. The first two components of this PhD research which culminated in the development and publication of two manuscripts are presented in Chapter 2. Chapter 3 describes the research objectives and design, as well as the methods for data collection and analysis. The results addressing each objective of the third component of this work are presented in Chapter 4. Finally, Chapter 5 discusses the findings from the cross-sectional study, the public health significance of the findings and makes recommendations for future research.

Chapter 2: Literature Review

In Australia, lymphoedema most commonly develops after treatment for cancer, and is one of the most feared side effects of cancer treatment [12]. Treatment for the most common male and female cancers, prostate and breast cancer, respectively, place patients at risk of developing lymphoedema. Since one in four males and one in nine females are diagnosed with these cancers before the age of 85, the public health burden of lymphoedema in Australia is significant [13]. In addition, lymphoedema is also a concern for other common cancers including melanoma and gynaecological cancers [2].

Improving health outcomes and quality of life for those with lymphoedema requires an understanding of the longitudinal impact of the condition on patients, identification of the most effective treatments, and consideration of the burden associated with treatment, in the context of patients' daily lives. This literature review begins by describing lymphoedema symptoms, incidence and prevalence, and risk factors. The physical, psychological and social impacts of lymphoedema on patients' quality of life are then discussed, with the peer-reviewed publication that resulted from work undertaken in exploring the quality of life impacts of lymphoedema included in this section (manuscript 1).

Improving symptoms and overall quality of life while living with lymphoedema often require patients to make a significant commitment to treatment and self-management, yet clear evidence-based treatment guidelines are lacking. In order to summarise the most current evidence relating to mainstream treatment effectiveness, a critique of existing literature and systematic reviews of lymphoedema treatment is presented. The use of CAM is also discussed, and the second manuscript written and published as part of this PhD follows.

The impact of treatment adherence on treatment effectiveness is explored, and factors associated with treatment adherence are discussed, with consideration of relevant health behaviour models. A new conceptual model is presented, depicting associations between a range of factors and treatment adherence and illustrating how

these factors fit with other health behaviour models. The chapter concludes by highlighting the issues that have been identified in previous research as likely barriers to effective treatment and long-term lymphoedema management and highlighting gaps worthy of further research.

PART ONE - LYMPHOEDEMA

2.1 BACKGROUND

Lymphoedema is a chronic condition characterised by impaired drainage of lymphatic fluid, commonly resulting in swelling and skin changes [14]. Lymphoedema is referred to as primary or secondary lymphoedema depending on its origin. Primary lymphoedema is an inherited abnormality or disorder of the lymphatic system and typically manifests either at birth, in adolescence or at middle age [15,16]. Secondary lymphoedema develops following trauma or injury, when the lymphatic system is damaged or blocked [17]. While the most common cause of secondary lymphoedema worldwide is the parasitic infection filariasis, in Australia and other developed countries secondary lymphoedema most commonly develops following treatment for cancer.

The International Society of Lymphology (ISL) details a four-stage classification system to describe lymphoedema status [18]. Stage 0 refers to a sub-clinical condition where lymphatic transport is disrupted but there is no evidence of physical symptoms. Stage 1 represents swelling that decreases with elevation alone, and when the skin is compressed, an indentation may remain ("pitting oedema"). Lymphoedema that does not respond to elevation, is chronic in nature and where pitting is evident is categorised as Stage 2. Stage 3 lymphoedema refers to severe swelling with the absence of pitting, and with possible skin changes including rashes, fibrosis, and seeping. Further, within these stages, when available, severity of lymphoedema is classified as minimal, moderate or severe, dependent on limb volume difference (<20% increase, 20-40% increase, >40% increase, respectively) compared with the unaffected limb, when available [18]. In addition to swelling, physical symptoms of lymphoedema can include pain, stiffness, numbness, heaviness, tightness and reduced strength and range of motion in the affected limb [2].

People with lymphoedema commonly report worsening of symptoms in hot weather, or when the limb is overused or restricted to a certain position, for example, sitting all day without elevation [19,20].

2.1.1 INCIDENCE AND PREVALENCE

Primary lymphoedema can develop as a symptom of a range of congenital syndromes, making the incidence difficult to quantify. However, the prevalence worldwide is estimated at 0.1-2% [15]. Secondary lymphoedema typically affects the limbs but can also develop in the trunk, head, neck and genital areas. While secondary lymphoedema incidence estimates vary widely (from 5 - 70% depending on cancer types), it is conservatively estimated that at least 20% of melanoma, breast, genitourinary and gynaecological cancer survivors will develop secondary lymphoedema following cancer treatment [2].

In Australia, one in four males and one in nine females are at risk of developing prostate and breast cancers during their life, respectively [13]. In addition, 1 in 18 persons are at risk of developing melanoma and 1 in 23 women are at risk of being diagnosed with any type of gynaecological cancer [13]. Five year survival rates for these cancers vary between 67 - 92% [13,21]. This highlights the public health burden associated with secondary lymphoedema, with more than 8,000 Australians expected to develop the condition each year [2]. One study estimated a prevalence of lymphoedema in the general population of 1.33/1,000 [3]. However, this estimate was based on cases identified by an urban health authority and is likely to be an underestimation of the true prevalence, not accounting for unreported cases [17].

2.1.2 RISK FACTORS

A wide range of possible risk factors associated with the development of secondary lymphoedema following cancer treatment has been investigated [2,22,23]. The current evidence highlights a number of factors that may increase lymphoedema risk, but does not enable prediction of who will or will not develop secondary lymphoedema. Radiotherapy and extensive surgical treatment, particularly resection of lymphatic vessels and lymph node removal, compromise the flow of lymphatic fluid, causing lymphoedema [24]. Positive associations between chemotherapy and lymphoedema have also been reported in a number of studies [25–27]. It is widely accepted that the use

of conservative treatment, such as sentinel lymph node dissection rather than full axillary clearance, reduces lymphoedema risk [28].

Associations between patient- and disease-related factors and lymphoedema risk are less clear [2,29]. Whilst some studies have reported that higher body mass index (BMI) increases risk of secondary lymphoedema [19,25,30], others have found no association [31,32]. Mixed findings have also been reported for the associations between lymphoedema risk and comorbid conditions, age and other demographic factors [2]. Considering the discrepancies in findings of previous studies, as well as advances in cancer treatment, there is a clear need for continued research attention on this topic, particularly through prospective cohort studies.

2.1.3 LYMPHOEDEMA PREVENTION

Although lymphoedema prevention guidelines exist, these are based on physiological knowledge of the lymphatic system and common-sense reasoning, rather than scientific evidence [2,28]. The broader principles that underpin prevention guidelines are: the production of lymph, which is proportional to blood flow, should be minimised, and additional blockages to lymph transport should be avoided [28]. Patients are therefore advised to avoid situations and activities, which increase blood and lymph flow (e.g., excessive heat) or obstruct the lymphatic system (e.g., tight clothing or jewellery). Specific guidelines to prevent lymphoedema include: avoiding blood pressure readings and injections in the affected region, excessive heat, sunburn, flight or long-distance car travel, activities which may cause skin injuries (e.g., gardening), constrictive clothing and vigorous exercise [28]. Avoidance of exercise has also been recommended previously. However, recent good quality evidence indicates that lymphoedema is neither initiated nor worsened by exercise [2]. Considering the general health benefits of physical activity and the potentially positive impact of other recommended restrictions on patients' daily life, it is important to determine for which factors there is, indeed, evidence of increased risk of lymphoedema and amend guidelines where necessary.

2.2 IMPACT OF LYMPHOEDEMA ON QUALITY OF LIFE

Previous research highlights the physical, psychological and social implications of lymphoedema and the impact on quality of life. As discussed above, physical

symptoms include pain, heaviness and tightness, and reduced range of movement. A review of the literature investigating psychological and social sequelae of lymphoedema following breast cancer reported many factors which contributed to reduced quality of life of those with lymphoedema [33]. Frustration, distress, anxiety and depression were among the psychological symptoms found to impair quality of life. Reduced function, mobility and physical ability to perform simple daily activities (e.g., pulling up/down a zip, grocery shopping, exercise, and social activities) can be frustrating and lead to a perceived loss of control [33]. For some patients, the chronic nature of secondary lymphoedema and the inability to hide physical symptoms and loss of function can make it even more distressing than the initial cancer diagnosis and associated treatment [6,7].

The psychosocial impact of lymphoedema can adversely affect personal, social and work relationships. Adequate social support and pre-existing coping strategies within the families of those who have lymphoedema have been associated with improved social functioning and psychological wellbeing of patients [33]. Unfortunately, a study of the experiences of women with lymphoedema found levels of support, acceptance and adjustment in intimate relationships varied widely [34]. In addition, many patients report significant difficulty in and disruption to intimate and sexual relationships [35,36]. Social functioning can be limited if patients give up hobbies and restrict social activities [33,34], either to avoid worsening of symptoms (e.g., outdoor sporting activities) or to avoid uncomfortable social situations (e.g., friends reacting insensitively to swelling). In some cases, people with lymphoedema have to adapt or change jobs or cannot work at all due to their symptoms [34]. This can increase the financial burden on patients and their families and be a source of additional stress and frustration [6].

The majority of the studies investigating the broader impacts of lymphoedema on quality of life has involved women with breast cancer and consequent upper-limb lymphoedema (ULL). Many symptoms and their associated impact on daily life may be similar for patients with secondary ULL and LLL [37]. However, evidence based on ULL cannot be directly transferred to LLL due to differences in limb size, volume and functions between the upper- and lower-limbs [3].

The limited research involving patients with LLL suggests patients can have difficulty walking and sitting, and performing self-management treatment components, such as massage and putting on compression stockings. Another concern, likely to be of particular importance to women with lymphoedema following gynaecological cancers, is the impact of the condition and associated symptoms on body-image, intimacy and sexual function [38].

To progress the knowledge in this area, a systematic literature review of studies investigating the impact of LLL on quality of life was undertaken and formed the first component of this PhD research [9]. The review was published in *Expert Reviews of Pharmacoeconomics and Outcomes Research* and is included below in Section 2.2.1.

2.2.1 QUALITY OF LIFE OF WOMEN WITH LYMPHOEDEMA FOLLOWING GYNAECOLOGICAL CANCER

PART TWO – LYMPHOEDEMA TREATMENT

Lymphoedema is considered a progressive and incurable condition, requiring ongoing attention, self-management and long-term treatment [25,39,40]. Without treatment, lymphoedema may progress and result in serious complications including infections and skin changes, reduced immunity and impaired mobility [29]. Currently, there is no cure for lymphoedema. Treatment strategies aim to reduce swelling, prevent progression, reduce risk of infection and alleviate associated symptoms [2]. Treatment effective in improving symptoms has been shown to reduce the impact of lymphoedema on daily activities, self-image and quality of life [34].

A range of mainstream and CAM treatments for lymphoedema exist. Mainstream therapies including complex physical therapy (CPT), MLD, compression (bandages, garments and pumps), low-level laser and exercise, are the most widely prescribed forms of lymphoedema treatment [41]. Surgery is typically only used for patients who are not responding to more conservative treatment [42]. While CAM treatments are less often prescribed for lymphoedema treatment, emerging research suggests that many patients use a range of CAM treatments and perceive some to be effective at improving symptoms (see section 2.4).

2.3 MAINSTREAM TREATMENT

Although research has been undertaken investigating the effect of different mainstream treatment methods on lymphoedema, inconsistent treatment guidelines exist; there has been little progress in determining the most effective treatments. The range of available treatment options has resulted in a number of studies of lymphoedema treatment, most of which (n = 163) have been included in at least one of the more than 20 reviews conducted to summarise the effect of lymphoedema treatment. The following presents a critique of these reviews, beginning with a summary of findings for each treatment, followed by evaluation of the quality of the review process undertaken and identification of gaps in the research related to lymphoedema treatment.

2.3.1 LITERATURE SEARCH

The reviews were identified through searches conducted in Medline, Pubmed, CINAHL, and Cochrane Database of Systematic Reviews. The main search terms were “lymphoedema or lymphedema”, “treatment or therapy” and “systematic review or literature review”. Additional search terms used were specific treatment strategies “complex physical therapy, complex decongestive therapy, manual lymph drainage, laser therapy, compression, surgery, massage, pneumatic pump, exercise” to ensure reviews assessing any lymphoedema treatment strategy were identified. In addition, internet searches were undertaken to identify any reviews commissioned by government and/or lymphoedema organisations but not published in journals, and therefore unavailable through electronic databases. The abstracts of 206 manuscripts were reviewed against the criteria below (see 2.3.2) and the full text versions of 23 potentially suitable reviews were retrieved.

2.3.2 INCLUSION CRITERIA

Reviews were included if the following inclusion criteria were met:

- A focus of the review was the effectiveness of lymphoedema treatment
- The reviewers conducted and reported on electronic literature searches
- Inclusion and exclusion criteria were defined and reported
- The reviewers applied and described a method of assessing methodological quality of included studies.

2.3.3 SEARCH RESULTS

Seventeen reviews met the inclusion criteria outlined above, with six excluded because the review did not focus on the effect of lymphoedema treatment effectiveness. One review paper [43] was a focussed summary of findings from a more extensive review undertaken by Oremus et al. [44]. The full review was included rather than the summary, leaving 16 reviews included in this critique. Fifteen reviews focussed on mainstream treatment types, while one review concentrated on self-management strategies. Eleven reviews included studies of a range of lymphoedema treatment strategies. The remaining five reviews were single-focus, with two reviewing studies of pneumatic compression [45,46], and one each on the use of exercise [47], surgery [48] and benzopyrones [49] to treat lymphoedema. The sixteen reviews were

published between 1998 and 2012 and included discussion of 158 primary studies of lymphoedema treatment, published between 1966 and 2011. An overview of review characteristics, including eligibility criteria and methods for assessing study quality, is presented in Table 2.1.

Table 2.1

Overview of included studies

Review	Search period	Number of studies	Eligibility Criteria	Method for Assessing Study Quality
Multi-focus reviews – including studies investigating a range of treatment types				
Megens 1998	1966-1997	13	Treated for BC Secondary LE in at least one arm IV=conservative treatment DV=limb size	Sackett's rules of evidence (adapted)
Kligman 2004	1966-2002	9	RCTs or systematic review of RCTs Measured effect of treatment on arm volume, symptom control, QoL or cosmetic results	Practice Guidelines Development Cycle
Preston 2004	Up to 2008	3	RCTs only, >6 month follow-up LE limb >10% compared with normal limb, bilateral LE objectively assessed Cancer patients completed treatment >6 months prior CB studies – no CB within 6 months prior	Cochrane review criteria
Moseley 2007	NS	36	Secondary LE following BC treatment Recurrent cancer or primary LE excluded	Quality scale assessment tool
Hayes 2008	2005-2007	19	Secondary LE following cancer treatment Treatment completed >6 months prior LE defined by authors' objective assessments or diagnosed by HP	NHMRC levels of evidence
Devoogdt 2009	Up to 2009	15	RCTs, pseudo-randomised and non-randomised experimental trials Patients with arm LE Unclear criteria relating to treatment type and outcome measures	NHMRC levels of evidence PEDro scores
Karki 2009	1998-2008	14	RCTs Secondary LE after BC 'Physiotherapy treatments' - diet, surgery and medical treatments excluded	Internal validity criteria Level of evidence categories

Oremus 2010	1990-2010	36	RCTs or observational studies with comparison groups Secondary lymphoedema All treatment, except surgery and drug therapy	Jadad scale Newcastle-Ottawa scale
McNeely 2011	1980-2009	25	RCTs conservative or dietary intervention >80% of participants with secondary LE following cancer LE vol as primary outcome	Jadad scale (modified)
Lasinski 2012	2004-2010	26	Complex decongestive therapy Patients with lymphoedema Case series if including >10 cases 1 case report on genital LE due to paucity of literature	PEP guidelines
Ridner 2012	2004-2011	16	Primary or secondary LE Research results or expert opinion Lymphoedema self-care	PEP guidelines
Single focus reviews – including studies of a single treatment type				
Badger 2003	Up to 2003	15	RCTs only LE limb >10% compared with normal limb, bilateral LE objectively assessed Cancer patients completed treatment >6 months prior No CPT within 6 months prior	Cochrane review criteria
Rinehart-Ayres 2010	Up to 2007	8	Secondary ULL following BC Treatment provided by HP using compression pump Measurements pre/post treatment	Sackett's rules of evidence
Kwan 2011	2004-2010	15	RCT, cohort or case-control study, meta-analysis, or systematic review LE as primary or secondary outcome Classification of exercise as resistance, aerobic or physical therapy	PEP guidelines
Cormier 2012	2004-2010	19	Surgery for lymphoedema treatment >8 patients	QADAS
Feldman 2012	2004-2011	10	Research study Pneumatic compression Patients with lymphoedema >10 cases	Bandolier strength of evidence guidelines

BC: breast cancer; LE: lymphoedema; ULL: upper-limb lymphoedema IV: independent variable; DV: dependent variable; RCT: randomised controlled trial; CPT: complex physical therapy; CB:compression bandaging; QoL: quality of life; NHMRC: National Health and Medical Research Council; HP: health professional; QADAS: Quality Assessment of Diagnostic Accuracy Scale; PEP: Putting Evidence into Practice.

2.3.4 METHODOLOGICAL QUALITY

Reviews were assessed against methodological quality criteria to evaluate rigour. The Cochrane Collaboration provides a tool for assessing risk of bias in the design and execution of randomised, controlled trials (RCTs) [50]. The tool specifies factors that should be assessed for the risk of selection (sequence generation and allocation sequence concealment), performance (blinding of participants and personnel), detection (blinding of outcome assessment), attrition (incomplete outcome data), and reporting (selective outcome reporting) biases, as well as other potential sources of bias (any bias not assessed in other domains). The consideration of these factors by reviewers is summarised in Table 2.2.

Only one of the sixteen reviews, a Cochrane Systematic Review [29], assessed studies against all of the above criteria, and reported the authors' judgement of risk of bias for individual studies. Another Cochrane Systematic Review [49] appeared to assess studies for risk of selection, performance, detection and attrition bias, detailing randomisation and blinding processes, and describing reasons for participant withdrawals. However, the possibility of selective outcome reporting was not discussed, and the reviewers did not make any explicit judgement of risk of bias in individual studies. A further four reviews limited study inclusion to RCTs or non-randomised experimental trials [51–54]. Of these, three considered the impact of randomisation processes, blinding and attrition on the risk of bias in included studies [51–53], and considered these factors when reporting results.

The remaining ten reviews included observational, as well as experimental studies. There were numerous tools used to assess the methodological quality of observational studies, focusing on different strengths and weaknesses of study design. In order to critique the methods, results and conclusions of these reviews, they were assessed for their consideration of a number of factors relating to review protocol. These factors, and the reasons for their importance in reviewing the quality of available evidence, are described below:

- study eligibility criteria – consideration of the inclusion and exclusion criteria and the influence these have on representativeness of the sample and generalisability of results;

- randomisation procedures (for RCTs) – identification of randomisation procedures, whether or not randomisation was successful, and whether there were any systematic differences between study groups at baseline;
- methods for measuring lymphoedema – identification of the methods used to measure lymphoedema (e.g., water displacement method to measure limb volume), and the impact of different methods on the appropriateness of comparing results between studies;
- adequate description of interventions – identification of treatment protocol and consideration of the impact of different protocols on results;
- follow-up periods – ability to determine whether positive results were maintained over time, as well as identifying adverse effects;
- details of patients lost to follow up – reasons for drop-outs and any differences between those who completed the intervention and those who withdrew from the study;
- statistical pooling (meta-analysis) – consideration of heterogeneity in study design and appropriateness of combining results.

An overview of each review and its consideration of these factors is presented in Table 2.3. Reviews taking these aspects of study design into account when reporting study results and forming conclusions about treatment effectiveness were considered to be of higher quality.

Table 2.2

Reviewers' consideration of Cochrane Collaboration criteria for assessing risk of bias

Review	Random sequence allocation	Allocation concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective reporting	Other sources of bias
Badger 2003	X	X	X	X	X		
Preston 2004	X	X	X	X	X	X	X
Oremus 2010	X	X	X		X	X	
Rinehart-Ayres 2010	X[a]	X[a]			X[b]		X
Devoogdt 2009	X	X	X	X	X		X
McNeely 2011	X	X		X	X		
Karki 2009	X	X	X	X	X		X
Megens 1998				X	X		X
Cormier 2012							
Moseley 2007							
Hayes 2008					X[c]		
Kligman 2004				X			
Kwan 2011	X[d]			X[e]			
Lasinski 2012				X	X[f]		
Ridner 2012							
Feldman 2012							

[a]discussed group differences at baseline, but not specifically random sequence allocation or allocation concealment (adequate randomization)
[b] evaluated information about attrition of subjects (incomplete outcome data)
[c]commented on characteristics of those lost to follow-up for CPT but not other treatments
[d]commented on lack of randomization in one study, but not clear whether considered for all studies
[e]commented on blinding in some studies but not all
[f]listed 'no drop outs' as a strength in two studies, not clear whether considered for all studies
- - - Reviews above dashed line met more criteria and were considered higher quality reviews.

2.3.5 TREATMENT EFFECTIVENESS

Where possible, review findings have been grouped according to treatment type, as classified by the review authors. The treatment types included in each review are presented in Table 2.4. Where review authors did not group studies according to treatment types, findings were grouped according to the following definitions of treatments (adapted from A. L. Moseley, Carati, & Piller, 2007)[55]:

Complex Physical Therapy (CPT) – a period of intensive treatment or a treatment program involving at least two of the following: MLD, massage, compression bandaging, prescribed exercises.

Manual Lymphatic Drainage (MLD) – light massage techniques applied by a health professional, to encourage removal of excess interstitial fluid, increase lymphatic transport and soften fibrotic induration.

Self-massage – Similar massage techniques to MLD, applied by self or another person (e.g., partner).

Laser therapy – low intensity wavelengths, either in a scanning or spot laser device.

Pneumatic compression pump (PCP) – single- or multi-chambered pumps that envelop the limb, inflating and deflating with differing cycles and pressures.

Compression bandaging (CB)– a gauze sleeve, soft cotton wrap or high density foam and 2-3 layers of short-stretch bandaging.

Compression garments (CG) – compression sleeve or stocking with graduated pressure, from greatest compression at distal end of the limb to least compression at the proximal end.

Prescribed exercises – progressive, resistive or sequential exercises prescribed with aim of varying total tissue pressure to encourage lymphatic drainage.

Surgery – any surgical technique used to treat lymphoedema.

Other – all other treatment types, including pharmaceutical and dietary interventions, heat therapy, elevation, electrical stimulation, ultrasound, and CAM therapies.

Table 2.3

Assessment of study quality in lymphoedema treatment reviews

Review	Cochrane Criteria*	Eligibility criteria	Randomisation procedures	Measurements of LE	Intervention description	Follow up periods	Details of drop outs	Meta-analysis
Badger 2003	5/7	X	X	X	X	X	X	
Devoogdt 2009	6/7	X	X	X	X	X		
Karki 2009	6/7		X	X	X	X	X	
McNeely 2011	4/7		X	X	X	X	X	X
Megens 1998	3/7	X		X	X	X	X	
Oremus 2010	5/7	X	X	X	X	X	X	
Preston 2004	7/7	X	X	X	X	X	X	
Rinehart-Ayres 2010	4/7	X	X	X	X	X	X	
Cormier 2012	0/7			X	X	X		
Feldman 2012	0/7			X	X			
Hayes 2008	1/7			X		X	X	
Kligman 2004	1/7			X	X	X		
Kwan 2011	2/7			X	X	X		
Lasinski 2012	2/7			X	X	X		
Moseley 2007	0/7	X			X	X		
Ridner 2012	0/7			X	X	X		

- - - Reviews above dashed line met more criteria and were considered higher quality reviews, with reviews listed in alphabetical order.

LE: Lymphoedema

* Cochrane Criteria: Random sequence allocation; Allocation concealment; Blinding of participants and personnel; Blinding of outcome assessment; Incomplete outcome data; Selective reporting; Other sources of bias. Score out of 7 indicates how many of these criteria were met by each review.

Table 2.4

Treatment types included in reviews

Review	CPT	MLD	CB	CG	SAM	Laser	PCP	Exercises	Surgery	Other
Megens 1998	X			X			X			X
Badger 2003										X
Kligman 2004	X			X			X			X
Preston 2004		X	X	X						
Moseley 2007	X	X	X	X		X	X	X		X
Hayes 2008	X	X				X	X	X	X	X
Devoogdt 2009	X	X	X	X			X	X		
Karki 2009		X	X	X		X	X			X
Oremus 2010	X	X	X	X		X	X	X		X
Rinehart-Ayres 2010							X			
Kwan 2011								X		
McNeely 2011		X	X	X		X	X	X		X
Cormier 2012									X	
Feldman 2012							X			
Lasinski 2012	X	X	X							
Ridner 2012					X		X	X		X

CPT: Complex physical therapy; MLD: Manual lymphatic drainage; CB: Compression bandaging; CG: Compression garments; SAM: Self-administered massage; PCP: Pneumatic compression pumps; Other: pharmacological therapies, ultrasound, microwave heating, electrical stimulation, dietary interventions, kinesiotaping and skin care.

2.3.6 COMPLEX PHYSICAL THERAPY

CPT, also known as Complex Decongestive Physiotherapy (CDT), is a two-phase treatment program combining multiple strategies. Foldi et al. (1989) originally described CDT as consisting of five parts of equal importance; skin care and hygienic

measures to eradicate infection, MLD, compression bandaging, and remedial exercises for a period of approximately four weeks, followed by prescription of a custom-made compression garment[56]. The compression garment is considered the second phase of treatment, prescribed with the aim of maintaining initial reductions in volume gained during the first phase of the treatment. Early studies of CDT [56] suggested volume reductions could be achieved following the first phase in 95% of patients with ULL following treatment for breast cancer. Further, of the 177 patients (total at study commencement = 399) who completed the 3 year follow up period, 54% were able to fully maintain volume reductions and 35% showed only partial relapse (lymphoedema did not return to pre-treatment volumes). Of note, the 10% of patients who had a full relapse had not complied with the maintenance phase of treatment[56]. However, since this early work, researchers internationally have combined multiple forms of various lymphoedema treatments to form an intensive period of treatment, called Complete Decongestive Therapy, Combined Physical Therapy, Decongestive Lymphatic Therapy or Complex Physical Therapy. For consistency, it will be referred to herein as Complex Physical Therapy (CPT), as defined by Casley-Smith & Casley-Smith [57].

Seven reviews included studies investigating the effectiveness of CPT, with sample sizes ranging from 14-537. There was considerable variation in treatments prescribed, as well as outcome measures and reporting methods used. CPT was delivered for periods of five days to four weeks and follow up periods varied between 1-13 months. The studies involved a range of treatment protocols, with MLD ranging from 30-60 minutes, daily to three times per week, and the use of compression being applied through bandages, garments, and/or pumps. Limb exercises and skin care were considered part of the CPT intervention in some studies, but not all.

Outcome measures of treatment effectiveness were most commonly objective measures of limb circumference and/or volume, measured by circumferences from 1-8 points on the limb (in some cases used to estimate volume using the truncated cone method)[2,54,58,59], water displacement [2,54,58,59], and less often, perometry and tonometry [2]. Outcomes, when reported (some did not report actual results when they did not meet statistical significance criteria), were reported either as absolute reductions (mls) in limb volume or as percentage reductions compared with baseline measures.

Mean volume reductions reported in the seven reviews were 3-66% following treatment, although the clinical significance of these changes was unclear. Nonetheless, conclusions reached by the reviews suggest CPT is effective for treating patients with lymphoedema of varying degrees (mild, moderate or severe), early or late onset, recent or chronic, in patients with or without active cancer, and in palliative care [59]. Results from studies of CPT with follow up periods indicated ongoing use of compression was required to maintain positive results [59].

In addition to limb volume, some studies also explored the effect of CPT for improving subjective symptoms [44,54,55,59], with inconsistent results reported by the studies included in the reviews. Use of CPT was associated with reductions in pain, tightness, heaviness, pins and needles, cramps and tension, and improvements in quality of life scores [55,59] in some studies, while others found no difference in experiences of symptoms between treatment and control groups [44,54]. Overall, the evidence suggests the use of CPT may improve symptoms and quality of life, although this is clearly an issue requiring further investigation. That is, clinically relevant outcomes including patients' responses to treatment, changes in symptoms, adverse effects, and patient compliance need to be included in future studies evaluating effect of CPT [51,54].

Despite differences in methods used to assess methodological quality, no review considered any studies of CPT to be high quality, and all discussed the methodological limitations of included studies. Limitations included: inconsistencies in defining and measuring lymphoedema [44,54,58,59]; varied treatment protocols and bundling of interventions [44,59]; lack of blinding of participants and assessors [51,58,59]; small sample sizes [44,54,59]; poorly stated exclusion criteria [55]; questionable representativeness of samples [2]; lack of follow up [44,59]; lack of accounting for attrition bias [2]; lack of measures of personal, treatment and behavioural factors [2]; and lack of measures of symptoms and quality of life [51]. While studies investigating the use of CPT have shown positive results, most reviews cautioned that these limitations need to be considered when interpreting findings.

2.3.7 MANUAL LYMPHATIC DRAINAGE

MLD refers to the use of massage on the limb and trunk, aiming to stimulate normal lymphatics, to encourage draining of excess fluid from the affected area [60,61]. The

technique was first presented by Dr. Emil Vodder in 1936 [60,61], as very specific hand movements, applying light pressure to the skin, in a distal to proximal manner. More recently, Vodder's method has been modified by others, resulting in a range of techniques being referred to as MLD [61].

Seven reviews included studies investigating the use of MLD. Of these reviews, only one referred to two studies investigating MLD use alone (with no other concurrent treatment), and these studies had very small samples of 12-17 people. All other studies included in the reviews combined MLD use with additional treatments, most often compression (bandaging, garments or pumps), aiming to determine whether MLD provided any additional benefit to patients beyond that achieved by compression (or other treatment) alone. Sample sizes in these studies varied widely (n = 11-357), as did treatment protocols. MLD techniques included the Vodder technique, Casley-Smith method, and other modifications, and were administered for 30-80 minutes, 1-2 times per day, 2-7 days per week, for up to 12 weeks. Follow up periods were between 6 and 12 months.

Results about MLD effectiveness conflicted across individual studies. Four reviews concluded that there was not sufficient evidence to support MLD effectiveness [29,44,51,53]. However, three reviews, including a meta-analysis of the addition of MLD to compression therapy compared with compression alone, suggested MLD provides additional benefit to patients [52,55,59]. Moseley et al. (2007) suggested MLD alone contributed to volume reductions of 104-156ml, and when used with compression demonstrated volume reductions of 47-250ml. It was reported these reductions equated to percentage reductions of 48%-84%. MLD was also shown to be effective in improving quality of life and associated lymphoedema symptoms, when used in conjunction with compression garments, bandages and/or pumps [55,59]. Findings from a meta-analysis [52] demonstrated a statistically significant benefit from the addition of MLD to compression therapy (SMD: 0.37; 95%CI: 0.07-0.67; p=0.02), but suggested this effect may be smaller than estimated by some individual studies, and should be considered in terms of the burden (time and financial) to patients. Conclusions from two reviews supporting MLD use suggested treatment should start with compression therapy, but when response is less than optimal or compression therapy is not well tolerated, MLD provides an appropriate alternative [52,59].

A number of issues are likely to contribute to the inconsistencies in findings between reviews. The use of different approaches for assessing methodological quality results in the identification of different weaknesses in study design and reporting. Whilst all reviews acknowledge the limitations of studies exploring MLD use, only two reviews differentiated between results based on study quality, showing that the studies reporting a significant effect of MLD were of low quality with inherent biases, while the higher quality studies found no additional benefit of MLD [51,53]. Further, differences in treatment protocols, study populations and study designs make comparisons inappropriate in many cases. The lack of methodological heterogeneity were cited in three reviews, as reasons for not undertaking meta-analyses [44,53,55]. Although the meta-analysis performed by McNeely [52] reported no statistically significant heterogeneity (p=0.36) and low variability among studies (i-squared value of 14%), it is important to note the review included only 5 studies, all of which had varying treatment protocols.

2.3.8 SELF-MASSAGE

Self-massage, also referred to as simple lymphatic drainage (SLD), is the patient-administered version of MLD. One review included studies of self-management strategies, with self-massage being considered one component of self-management. Three of the sixteen studies included in that review (n=10-1449) investigated the use of self-massage, with other studies focussing on exercise, compression, weight reduction, skin care, and combined self-management programs [62]. Findings from two cross-sectional surveys confirmed that self-massage is commonly used by patients (up to 66%) to manage their lymphoedema but did not report on effectiveness. Only one intervention study investigated the use of self-massage and skin care, with reports of patients' experiencing relief from symptoms and some reduction in arm volume after 3 months (size of reduction not reported).

2.3.9 LASER THERAPY

After findings in animal studies in wound healing suggested low level laser therapy (LLLT) accelerated regeneration of lymphatic vessels and stimulated lymphatic flow, LLLT using wavelengths of 650-1000nm was proposed for the treatment of lymphoedema [63]. Laser therapy is applied to the affected area in either spot or scanning laser form. Five reviews included between 2-4 studies of LLLT. Individual

studies involved 8-64 participants, with intervention groups receiving laser therapy 2-3x/week for 3-4 weeks, and control groups receiving either no treatment, sham laser or treatment with pneumatic compression. Volume reductions were achieved with both concentrated and scanning laser devices, and improvements in symptoms and quality of life were reported in 2 reviews [44,55]. Actual volume reductions following treatment periods were summarised in three reviews [2,44,55], and ranged from 1-19%. Continued reductions (9-29%) were demonstrated 3 months to 3 years following treatment [55]. Two reviews highlighted that when combined with exercise, treatment with LLLT demonstrated greater volume reductions than pneumatic compression [44,52]. However, these conclusions were based on results from a single study, limiting the strength of the evidence.

Although there is some evidence to support LLLT effect, the studies showing the greater volume reductions were small and had varied treatment protocols. The largest study (n=64) found volume reductions of >200ml in 31% of participants who had received two cycles of laser, compared with 4% of participants who only received one cycle of laser treatment, but differences between mean limb volume before and after treatment were not significant [2].

2.3.10 PNEUMATIC COMPRESSION

Pneumatic compression pumps (PCP) consist of pneumatic cuffs attached to an electric pump, and wrap around the limb(s). The pump is designed to mimic the intermittent compression of vessels that normally occurs during muscle contraction (i.e., during exercise) [64]. PCP vary in terms of timing (2 seconds-2 minutes), pressure (35-300mmHg) and compression type, which can be delivered by the pump uniformly through the whole cuff, sequentially via separate bladders inflating in sequence, or graded sequentially via different timing and pressure delivered through multiple bladders in the cuff. As there is no non-invasive way of measuring changes in lymph flow, the manner by which pneumatic compression works to move fluid, and which device is most suitable for lymphoedema treatment is not well understood [64]. It has been suggested that compression empties terminal lymphatics, allowing movement of fluid from the interstitium [64]. It is unclear whether pumps have any impact on fluid movement within the tissues, or assist with protein clearance [44,64].

Consequently, there is wide variation in the devices marketed for lymphoedema treatment.

There has been considerable attention given to the use of pneumatic compression for lymphoedema treatment, with ten reviews summarising the available evidence. A range of pumps was used in the studies included within any given review, with one review identifying nine different devices across twelve studies. Both uniform and sequential pumps were used with pressures ranging from 40-150mmHg. Pumps were applied for 20 minutes to 6 hours/day, 1-3 times/day, once a week to daily, with the longest treatment period being 6 months. Studies assessed the use of PCP alone, compared their use with other treatment types, or assessed their effect when combined with other treatments.

There is limited evidence to suggest pneumatic compression is effective in reducing limb volume in the short-term. Volume reductions (7-45%) have been reported following use of uniform and sequential PCP, with pressures between 40-160mmHg. Greater reductions have been achieved when the use of pumps was combined with other therapies, including MLD, compression garments or self-administered massage [55]. Volume reductions however have only been maintained with ongoing compression therapy, using pumps or compression garments [55,58].

Two reviews evaluated use of pneumatic compression devices, suggesting PCP were well-tolerated in low to moderate pressure ranges, perceived as effective by patients, and associated with improvements in self-perceived emotional and physical health [46,62]. No adverse events during or after the use of PCP were reported, suggesting home use is a safe alternative for people unable to access other treatment.

Four reviews found there was insufficient evidence to support efficacy of pneumatic compression, when compared with no treatment or other treatment types [45,53,54,62]. The other six reviews presented evidence of demonstrated volume reductions following pump use, but drew attention to significant methodological limitations. Although over 20 studies have investigated the effect of PCP for treating lymphoedema, the use of many different pump types, small sample sizes, different treatment protocols, and combined treatment programs has contributed to lack of consensus between reviews about the overall evidence in support of pneumatic

compression compared with other treatments, or the most appropriate timing, pressure or compression type, for lymphoedema treatment.

2.3.11 COMPRESSION BANDAGING AND GARMENTS

Compression bandages and garments are commonly prescribed for the treatment of ULL and LLL. Bandages are usually applied to the affected limb by another person, while compression stockings and sleeves can be self-applied. Foldi et al. (1989) suggest bandages counteract elastic insufficiency (resulting from the destruction of elastic fibres in lymphoedema), increase tissue pressure and subsequently, increase lymph flow. However, unless the trunk has been decongested and normal lymphatics stimulated, it is suggested any fluid drained from the limb to the trunk through the use of compression can increase trunk edema, further reducing lymphatic drainage from the limb in the long-term [56]. It has therefore been proposed compression therapy should be used in conjunction with MLD to prevent reaccumulation of fluid, rather than used as an initial treatment strategy [56].

Between 2-6 studies (n = 19 - 150) investigating the use of compression bandaging and/or compression garments were included in any one of the nine relevant reviews. Studies compared either bandages with garments, compression alone (bandages or garment), as a component of a combined treatment strategy (e.g., compression garments with MLD or self-massage), or assessed differences between high- and low-pressure bandages/garments.

Compression bandaging alone

Studies of compression bandaging included 29-90 participants, with bandages applied for a minimum of 24 hours and up to 19 days. Both low-pressure (20-30mmHg) and high-pressure (44-58mmHg) bandages were used. Despite differences in the review approach undertaken, the conclusions regarding the effect of bandaging were consistent across all reviews, suggesting the use of compression bandaging resulted in volume reductions in ULL and LLL, in the short and long-term [29,44,51,53,55]. Volume reductions up to 38% were achieved when bandages were used alone. The two reviews that reported on follow-up periods noted reductions achieved by bandaging were maintained up to 6 months post-treatment [51,52].

Compression garments alone

The use of compression garments to treat lymphoedema has been assessed in those with ULL and LLL. Sample sizes ranged from 19-150, garments (pressure: 30-40mmHg) were prescribed for day-time use only or for 24-hour use, and study periods varied from 2 weeks to 15 months. Although volume reductions up to 24% were reported following the use of compression garments [52,55], the quality of the studies investigating compression use alone was considered low by the majority of reviews, suggesting these findings should be interpreted with caution.

Compression (bandages or garments) combined with other treatments

The majority of studies investigating the use of compression involved multi-treatment interventions. Overall, review findings suggest there is evidence to support the effectiveness of compression garments and bandages, with greatest reductions (4-60%) being achieved when compression was combined with other physical therapies [53,55]. However, the grouping of different treatments makes it particularly difficult to identify which components of the interventions are effective.

2.3.12 EXERCISE

Exercise prescription for lymphoedema treatment typically consists of aerobic or resistance training, or programs combining both. Types of exercise investigated include limb exercises (with and without weights), abdominal and back exercises, hydrotherapy, pole-walking, and dancing. Earlier guidelines for the management of lymphoedema suggested exercise, in particular repetitive movements, may exacerbate symptoms, but the current evidence suggests otherwise [2,7,44]. Also, exercise has been found to have positive effects on physical and psychological factors [65]. Studies have assessed lymphoedema status before and after completing different exercise programs, to determine which exercises are most beneficial to patients, as well as to monitor the presentation of any adverse effects.

Seven reviews included between 1-15 studies of exercise interventions for the treatment of lymphoedema. Interventions evaluated in any one study included supervised and unsupervised exercise, full body and specific limb exercises, resistance and aerobic training. Studies included 10-141 participants with lymphoedema. Although approaches used to review the relevant literature differed, conclusions were consistent across all reviews. Regardless of exercise type, exercise did not exacerbate lymphoedema, and in many cases was associated with

improvements in symptoms and quality of life. There is some suggestion from small trials that resistance training, hydrotherapy and limb exercises can contribute to volume reductions (12-101ml), but much larger trials are needed to confirm these findings [55]. Identified weaknesses in the majority of exercise trials included small samples, moderate adherence (47-70%), evaluations completed by multiple therapists, lack of blinding of assessors, and difficulties measuring unsupervised exercise [47].

One review separated studies into exercise types and assessed findings based on study quality [47]. The recommendations from that review suggested resistance exercise was *likely to be effective* (highest current available level of evidence for exercise interventions), *benefits were balanced with harms* for combined resistance and aerobic exercise, and *effectiveness was not established* (lowest level of evidence) for other exercise (e.g., limb exercises). These recommendations are based on the weight of the available evidence and highlight the need for high quality research in this area, addressing the limitations of previous studies.

2.3.13 SURGERY

Surgical procedures used to treat lymphoedema include excisional procedures, lymphatic reconstruction and tissue transfer procedures. Excisional debulking procedures are an aggressive form of surgery, involving the removal of excess skin, adipose tissue and fibrous connective tissue, resecting the skin and soft tissue, and covering with a skin graft [48]. Reported complications following excisional procedures include hematoma, skin/flap necrosis, infection, deep vein thrombosis, loss of limb function and destruction of lymphatic vessels [48]. More recently, liposuction has been used to remove subcutaneous fat, reducing overall limb size [48,66]. Lymphatic reconstruction procedures are microsurgical procedures used to create anastomoses between lymphatic channels, lymph nodes and veins. Lymphaticovenular anastomosis (LVA) involves making small incisions to enable the creation of fine connections between lymphatics and subdermal venules. The procedure is less invasive than other forms of lymphoedema surgery and can be performed using local anaesthesia [48]. Tissue transfer procedures involve the transplanting of normal lymph nodes and vessels to the lymphoedematous area. Most commonly, lymph nodes from

an unaffected thigh are transplanted to the affected upper or lower-extremity, with anastomoses created between the normal lymph tissue and existing lymph vessels [48].

Studies of surgical procedures for the treatment of lymphoedema were only included in two reviews. Prospective studies included between 9-42 participants, while retrospective studies assessed outcomes of 9-1800 lymphoedema patients following surgical treatment for lymphoedema. The overall quality of study design and reporting was low, with most lacking comparison groups, having unreported participant rates, lacking selection criteria and absence of symptom assessment [48]. Nonetheless, significant volume reductions were achieved using excisional (18-118%), lymphatic reconstruction (2-59%) and tissue transfer procedures (up to 100%). Only one retrospective study of 9 patients who were treated with tissue transfer procedures reported an increase in limb volume of 13%. Although positive results were obtained following surgery, continued use of conservative treatment (e.g., compression garments) was required to maintain benefits long-term.

2.3.14 OTHER TREATMENT FOR LYMPHOEDEMA

Other treatments proposed and investigated for lymphoedema include pharmacological interventions, ultrasound, microwave heating, electrical stimulation, dietary interventions, kinesiotaping and skin care [2,44,49,52–55,58,62]. Four reviews included fifteen studies investigating the use of pharmacological treatments. Synthesis of the available evidence and resulting conclusions were consistent; the evidence does not support the use of benzopyrones or other pharmacological interventions for lymphoedema treatment [2,49,54].

Dietary interventions have been prescribed on the premise that reducing body fat may improve lymphoedema. Overall, studies suggested those who undertook dietary interventions resulting in weight loss, also demonstrated reduced arm volumes [2,44,52]. Conclusions made in the relevant reviews were that positive effects on lymphoedema were found following dietary interventions, and that health benefits are likely to extend beyond limb volume reductions, but suggest more research is needed to investigate long-term maintenance [2,44,52]. The paucity of research relating to the other treatment types precludes any conclusions being made regarding their use by lymphoedema patients.

2.3.15 KEY FINDINGS RELATING TO EFFECT OF MAINSTREAM TREATMENTS

A tabulated summary of review findings relating to each treatment type is presented in Table 2.5. For each treatment, the conclusions made in each review were considered to reflect an improvement in lymphoedema ('yes') following treatment, no improvement in lymphoedema ('no'), or inconsistent results precluding any solid conclusions being made.

When considering these findings alongside review protocols, there was no obvious explanation for the differences in the findings between reviews. Thirteen different methods, scales and sets of guidelines were used by reviewers to assess methodological quality of their included studies, with some reviewers using multiple scales. Although there was variation in the assessment of study quality and reporting of study details, these discrepancies did not impact significantly on the key findings reported between reviews and are therefore reported here.

The following key findings summarise the current available evidence, and identify the gaps needing further research attention:

- There is agreement among reviews that CPT is effective at reducing limb volume. The most effective components of CPT cannot be identified based on the current level of evidence. Further, factors influencing effectiveness are not well understood. It appears ongoing therapy is required to maintain initial reductions achieved by an intensive period of CPT.
- Reported effect of MLD on lymphoedema is inconsistent. MLD appears to be effective when used with compression therapy, but the available evidence does not support its use as a stand-alone treatment strategy.
- Limb volume reductions have been demonstrated following use of low-level laser therapy in some studies, but these results should be considered preliminary, with larger, better designed trials needed to support this evidence.
- Volume reductions have been achieved with the use of PCP, with greater reductions demonstrated when the use of pumps was combined with other treatments.

- Significant volume reductions have been demonstrated following the use of compression bandaging and garments in combined treatment programs, but the contribution of compression therapy alone, in reducing limb volume, is not well understood.
- More evidence is needed to determine whether exercise contributes to volume reductions, and if so, whether reductions are maintained long term.
- Use of surgical treatment for lymphoedema has resulted in significant volume reductions, but has the potential for complications and requires continued use of conservative treatment to maintain improvements.

2.3.16 LIMITATIONS OF REVIEWS OF MAINSTREAM TREATMENT LITERATURE

There was significant variation in review methodologies. Reviews had different inclusion criteria based on time periods, treatment types, study populations, selection criteria, and study design, although some overlap did exist, with multiple reviews including the same studies. Where crossover was evident and discrepancies between authors' conclusions existed, results from primary studies were assessed to determine the most appropriate conclusions.

Overall, the quality of studies investigating treatment for lymphoedema has been poor, both in terms of study design and reporting. There is suggestion the apparent lack of fundamental aspects of study design in some studies may be a result of poor reporting practices rather than inherent flaws in the research [44], but this cannot be assumed where the authors have not described methods adequately. The majority of studies have been cohort, case-control and cross-sectional studies, with few well-designed RCTs. Inconsistent methods for measuring lymphoedema, multiple outcome assessors, lack of blinding, small samples, and lack of follow-up periods were all cited as methodological limitations. Conducting inappropriate data analyses and the reporting of unadjusted results were also evident in many studies, increasing the potential for biased results [2,29,52,53]. These limitations of the majority of the studies included in previous reviews have led to underpowered results, a lack of generalisable findings and difficulties comparing results from studies of different treatments.

Table 2.5

Summary of treatment effectiveness results from included reviews

Review	CPT	MLD	CB	CG	SAM	Laser	PCP	Exercises[a]	Surgery
Badger 2003*									
Preston 2004		No	Yes	Yes					
Oremus 2010	Yes	Inconsistent	Yes	Yes		Yes	Inconsistent	No	
Rinehart-Ayres 2010							Yes		
Devoogdt 2009	Yes	Inconsistent	Yes	No			Inconsistent	Yes	
McNeely 2011		Yes	Yes	Yes		Inconsistent	Inconsistent	No	
Karki 2009		Yes	Yes	Yes		N/A**	No		
Megens 1998	Yes			Yes			Yes		
Cormier 2012									Yes
Moseley 2007	Yes	Yes	Yes	Yes		Yes	Yes	Yes	
Hayes 2008	Yes	Yes				Yes	Yes	Yes	Yes
Kligman 2004	No			Yes			No		
Kwan 2011								No	
Lasinski 2012	Yes	Inconsistent	Yes						
Ridner 2012					Yes		No	No	
Feldman 2012							Inconsistent		

Yes: Review concluded treatment resulted in improvements in lymphoedema; No: Review concluded treatment did not improve lymphoedema; Inconsistent: Review concluded the results from individual studies of treatment effectiveness were inconsistent; Blank: Treatment was not included in review

*Review of pharmaceutical treatments only – did not include any mainstream treatments **Decreases in lymphoedema between groups were not analysed

[a] For exercise interventions, no change in lymphoedema is considered a positive finding (i.e., no exacerbation of lymphoedema following exercise)
CPT: Complex physical therapy; MLD: Manual lymphatic drainage; CB: Compression bandaging; CG: Compression garments; SAM: Self-administered massage; PCP: Pneumatic compression pumps;

2.4 COMPLEMENTARY AND ALTERNATIVE MEDICINE

All of the reviews discussed above focussed on mainstream treatments, considered by health professionals' to be the most common forms of lymphoedema treatment [41]. However, the use of CAM therapies, in addition to or as a substitute, for mainstream therapies is commonly reported by cancer patients [67–69]. Although research on the use of CAM for lymphoedema treatment is limited, individual studies have investigated the use of acupuncture and the Sun Ancon Chi Machine [70,71], with positive effects on self-reported symptoms [70], and limb volume, respectively [71].

To explore the use of CAM therapies in more detail, secondary analysis using data from a cross-sectional study investigating the use of mainstream and CAM treatments by women with lymphoedema (n=95) following breast or gynaecological cancer was undertaken as part of this postgraduate research. The resulting peer-reviewed, published manuscript [10] describes the use, as well as perceived effectiveness, of mainstream and CAM therapies for the treatment of lymphoedema. The following manuscript outlines the common and varied use of a range of treatment types and reports the high perceived effectiveness of treatment by patients. These findings provide new information about patients' perceptions of lymphoedema treatment and highlight the need for further investigation into the reasons why patients choose to use such a wide range of treatments, many of which have received little research attention and thus have little evidence for their effectiveness.

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Short Report

Lymphedema After Breast or Gynecological Cancer: Use and Effectiveness of Mainstream and Complementary Therapies

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Abstract

Objectives: The purpose of this study was to describe the use, as well as perceived effectiveness, of mainstream and complementary and alternative medicine (CAM) therapies in the treatment of lymphedema following breast or gynecological cancer. Further, the study assessed the relationship between the characteristics of lymphedema (including type, severity, stability, and duration), and the use of CAM and/or mainstream treatment.
Methods: This was a cross-sectional study using a convenience sample of women with lymphedema following breast and gynecological cancers. A self-administered questionnaire was sent to 247 potentially eligible women. Of those returned (50%), 23 were ineligible and 6 were excluded due to level of missing data.
Results: In the previous 12 months, the majority of women (90%) had used mainstream treatments to treat their lymphedema, with massage being the most commonly used (86%). One (1) in 2 women had used CAM to treat their lymphedema, and 98% of those using CAM were also using mainstream treatments. Over 27 types of CAM were reported, with use of a chi machine, vitamin E supplements, yoga, and meditation being the most commonly reported forms. The perceived effectiveness ratings (1–7 with 7 = completely effective) of mainstream (mean ± standard deviation (SD): 5.3 ± 1.5) and CAM therapies (mean ± SD: 5.2 + 1.6) were considered high.
Conclusions: These results demonstrate that mainstream and CAM treatment use is common, varied, and considered to be effective among women with lymphedema following breast or gynecological cancer. Furthermore, it highlights the immediate need for larger prospective studies assessing the inter-relationship between the use of mainstream and CAM therapies for treatment success.

Introduction

Lymphedema is a condition characterized by impaired drainage of lymphatic fluid, commonly resulting in swelling and skin changes.[1] Mainstream or complementary and alternative medicine (CAM) treatments for lymphedema aim to reduce swelling, prevent progression, reduce risk of infection, and alleviate associated symptoms.[2] Early diagnoses, rapid initiation of treatment, and high adherence to treatment have been reported to optimize treatment success,[3] and lack of treatment has been associated with lymphedema progression.[2] Unfortunately, access to treatment, associated costs, and the time and/or discomfort associated with daily treatment is considered unacceptable to some and may influence treatment effectiveness.[4,5] The purpose of this study was to describe the use and perceived effectiveness of mainstream and CAM therapies in the treatment of lymphedema following breast or gynecological cancer.

Methods

Self-administered questionnaires were sent to 247 members of the Lymphedema Association of Queensland and were returned by half of them ($n = 124$). A further 29 participants were excluded due to ineligibility or missing data, leaving data from 95 participants for analysis.

Information on demographic characteristics, lymphedema characteristics, and lymphedema treatment types used were collected via a self-administered questionnaire. Twenty-two (22) treatment types were listed, and additional space was provided to record unlisted treatments. Treatment types were classified as CAM if they were considered an approach, practice, or product that did not fit within conventional or mainstream medicine.[6] Perceived effectiveness of treatments in improving symptoms of lymphedema was measured using a 7-point Likert scale, whereby 0 denoted "not at all effective" and 7 denoted "completely effective."

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Descriptive statistics were used to summarize personal and lymphedema characteristics of the sample. Unadjusted logistic regression was used to determine the relationship between mainstream or CAM treatment use, and personal and lymphedema characteristics. Statistical significance was set at <0.05 (two tailed) for all analysis. Data analyses were performed using SPSS version 17.0.

Results

Characteristics of the sample are presented in Table 1. In summary, all respondents were females and had undergone surgical treatment for breast (84%) and/or gynecological cancer (22%). Over two thirds (69%) reported household annual incomes of less than $50,000, and 63% were retired/on a pension.

Nearly 75% of the sample had upper-limb lymphedema, 18% had lower-limb lymphedema, and the remaining participants ($n=7$, 7%) had lymphedema in both upper and lower limbs. A range of lymphedema severities were reported, with 19%, 27%, and 13% of participants describing their lymphedema as mild, moderate, and severe, respectively. Those remaining (41%) reported experiencing a mixture of symptom severities over the involved limb segments. The majority (76%) described their lymphedema as fluctuating in stability, and most of the respondents (70%) reported having had lymphedema for longer than 5 years.

Table 2 provides the list of therapies used by participants in the previous 12 months. Of those who reported using CAM therapy in the previous 12 months (45% of sample), more than half reported using two or more forms and 98% also reported using some form of mainstream treatment. Use of a *chi* machine, *t'ai chi*, vitamin E supplements, meditation, and/or yoga were used by 21%–35% of those reporting CAM therapies, while other forms of CAM including selenium supplements, spiritual healing, reiki, naturopathy, acupuncture, and homeopathy were reported by 5%–11%. The perceived effectiveness of mainstream therapies (mean ± SD: 5.3 ± 1.5) and CAM therapies (mean ± SD: 5.2 ± 1.6) was similar ($p=0.53$).

Compared with women 65 years or older, the odds of using CAM were at least twofold higher for those aged 64 years or less ($p=0.05$). Those with stable lymphedema also had higher odds of using CAM (odds ratio [OR] = 4.95, 95% confidence interval (CI) = 1.27–19.35, $p<0.05$), compared with those who described their lymphedema as fluctuating. Although not statistically supported, employed women and women with

Table 1. Patient Characteristics of the Sample (n = 95)

Patient characteristics	n *(%)*
Age	
18–54 years	10 (10.5)
55–64 years	37 (40.0)
65 years and older	48 (50.5)
Area	
Major city	35 (38.4)
Regional area	42 (46.2)
Rural/remote area	14 (15.4)
Marital status	
Living with partner	64 (67.4)
Living without partner	31 (32.6)
Employment status	
Employed	20 (21.1)
Retired/disability pension	60 (63.1)
Home duties	15 (15.8)
Yearly household income	
$0–$50 000	55 (68.8)
$50,000 and over	25 (31.2)
Private health insurance	
Yes	75 (79.8)
No	19 (20.2)
Cancer type[a]	
Breast	80 (84.2)
Gynecological	21 (22.1)
Skin	3 (3.2)
Melanoma	2 (2.1)
Bowel	3 (3.2)
Lymphoma	2 (2.1)
Bone	1 (1.1)
Lipsarcoma	1 (1.1)
Lung	1 (1.1)
Number of cancers	
One cancers	76 (80.0)
Two cancers	18 (18.9)
Three cancers	1 (1.1)
Cancer treatment[a]	
Surgery	95 (100)
Radiation	69 (72.6)
Chemotherapy	37 (38.9)
Hormone	22 (23.2)
Other treatment	4 (4.2)

[a]Multiple responses possible.

Table 2. Treatment Types Used by People with Lymphedema, Classified as Mainstream or Complementary and Alternative Medicine

Mainstream treatment types
Compression garments/bandaging
Laser therapy
Limb exercises
Manual lymph drainage
Self-administered massage
Skin care
Ultrasound
Complementary and alternative medicine
Acupuncture
Aromatherapy
Bowen therapy
Chi machine
Chiropractic
Circulation booster
Detox water treatment
Homeopathy
Kinesiotape
Meditation
Naturopathy
Nurolink®
Osteopathy
Reflexology
Reiki
Spiritual healing
T'ai chi
Pilates
Yoga
Vegetable bristle body brushing
Vitamin and mineral supplements

yearly household incomes of $50,000 or more had higher odds of using CAM therapy (OR=2.41, 95% CI=0.86–6.79 and OR=2.43, 95% CI=0.92–6.39, respectively), compared with those who were retired or did home duties and those with incomes below $50,000 per year, respectively.

Discussion

Despite the high perceived effectiveness of mainstream treatment, about 1 in 2 women reported multiple mainstream treatments, and 1 in 2 also used at least one of the 22 CAM therapies to treat their lymphedema during the same period. CAM therapies may be used as an alternative treatment option following poor response to mainstream lymphedema therapies.[7] However, since almost all women in our sample reporting the use of CAM also used mainstream therapies during the same period, it seems more likely that CAM therapies were considered complementary rather than alternative.

Previous work by others has described the financial, time, and lifestyle burden of typical forms of mainstream treatment options.[8,9] Despite high perceived effectiveness ratings, the burden may be sufficient to encourage those with lymphedema to source alternative treatment options. This may be more likely for particular subgroups, such as younger women and those who are employed, who were more likely to use CAM treatments in this study. It could be assumed that treatment options scoring similar or higher effectiveness ratings that place lower burden on the women might become the sole or alternative forms of treatment, replacing mainstream options. Consequently, it seems plausible that while the forms of CAM treatment reported were perceived to be effective, multiple barriers prevented them from becoming alternative forms of treatment.

Conclusions

The generalizability of the results presented is limited to women who developed lymphedema following breast or gynecological cancer, and the cross-sectional design precludes the identification of specific treatment effects on lymphedema symptoms. All respondents were members of a support organization and may not be representative of the general secondary lymphedema population. In addition, there were insufficient data to explore the use and effectiveness of individual mainstream or CAM treatment modalities. Nonetheless, this work provides initial insight into the extent of mainstream and CAM use in the treatment of lymphedema following cancer, as well as the perceived effectiveness of such treatment from the perspective of the patient. Given the extent and range of CAM therapies used by women in this study, future research attention should be given to the inter-relationship between mainstream and CAM therapies for treatment success.

Disclosure Statement

No competing financial interests exist.

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2.5 LYMPHOEDEMA TREATMENT SUMMARY

Despite the large number of studies investigating mainstream lymphoedema treatment (n = 158), progress towards identifying the most effective treatments has been slow. The use of compression therapy alone, and combined with MLD, has been supported by RCTs [49,52]. Also of clinical importance, and supported by two well-designed and reported RCTs, is the finding that exercise does not exacerbate lymphoedema [72,73]. This evidence is important as previous lymphoedema prevention and management guidelines recommended that people with lymphoedema should avoid exercise to prevent worsening of symptoms.

Future research, aiming to confirm or refute findings of previous studies, must address their limitations to improve the quality of the evidence surrounding lymphoedema treatment effectiveness. Large, well-designed RCTs are needed, with sufficient numbers to enable subgroup analyses (i.e., to determine whether particular treatments are more effective at treating ULL compared with LLL, or mild versus severe lymphoedema). It has been suggested in several reviews that experimental interventions should be compared to 'standard lymphoedema treatment' [44], but it is evident from the wide range of treatment protocols in the reviewed studies that there is little consensus on what 'standard lymphoedema treatment' involves. In all studies, treatment protocols should be described in enough detail to enable replication in other study populations. Where blinding of participants and health professionals administering treatment is not possible due to the nature of the intervention, the blinding of outcome assessors would at least strengthen study design.

There is evidence of improvements in lymphoedema following the use of a range of different treatments, but regardless of treatment type, ongoing management is required to manage chronic symptoms. It is possible different treatments are more appropriate at different stages of the trajectory. Further, long-term outcomes are likely to be influenced by patients' adherence to treatment, yet little research attention has been given to adherence or factors influencing adherence. In addition to measuring objective changes in limb volume, the effect of treatment on patients' symptoms, as well as the time, cost and effort involved in undertaking lymphoedema treatment and self-management, should be considered. The following section summarises the available research in the area of treatment adherence.

PART THREE – LYMPHOEDEMA TREATMENT ADHERENCE

2.6 TREATMENT ADHERENCE

Early diagnosis, rapid initiation of treatment and high adherence to treatment (which often includes daily self-management tasks for patients) have been reported to optimise lymphoedema treatment success [74], and lack of any treatment has been associated with lymphoedema progression [2]. Whilst research on adherence to lymphoedema treatment is limited, adherence is considered an important aspect of the long-term management of many chronic conditions. Non-adherence to medical treatment is a common and persistent problem, reducing treatment effectiveness, impacting on patients' quality of life, and increasing health service costs [75,76]. Whether the patient is required to take medication, attend regular appointments with health professionals or continue self-management behaviours to treat their condition, their adherence to the prescribed treatment program is often important to achieve optimal results [77].

Non-adherence (also called non-compliance) was first recognised by Hippocrates, as a potential threat to the spread of infectious disease [78]. In the 1950's, non-compliance was again recognised by three physiologists as being a significant problem in effectively treating tuberculosis [78]. Following this recognition, researchers began to further explore the factors associated with non-compliance. Although the terms "compliance", "concordance" and "adherence" have been used interchangeably in the literature, their differences are defined here for clarity. "Compliance" is defined as conforming to a treatment program as prescribed by a health professional [79]. Negative connotations associated with the word "compliance", implying patients should submit to doctor's advice and play only a passive role in managing their treatment, have led to the use of other terms. In the "concordance model", developed by members of the Royal Pharmaceutical Society of Great Britain, the patient is seen as an active decision maker and the aim is for the patient to make informed, considered choices about treatment for their condition [76]. Similarly, it is suggested the term "adherence" reduces the power attributed to the health professional in the professional-patient relationship, and describes a process where the patient is an active participant in decisions relating to their treatment. The meaning of adherence

changes depending on the treatment requirements for a given health issue. While some acute conditions will only require adherence to a short term prescribed pharmacological treatment in order for treatment to be successful, a treatment protocol for a chronic condition may have several elements, including physical therapies, lifestyle changes and medications [77]. The increasing popularity of terminology that acknowledges the patient's involvement in their care reflects the growing understanding of the complexity of treatment adherence as a theoretical concept.

Treatment adherence is used here as an umbrella term to describe the process where the choices and behaviour of the patient correspond to what has been agreed upon with their health care provider regarding their treatment [77,79]. This definition acknowledges the importance of considering the patient's perspective and individual situation when developing the treatment program. There is argument that one of the greatest factors hampering progression in adherence research is the absence of the patient's perspective [76,80]. While it is useful to measure "compliance" when assessing treatment effectiveness (e.g., what level of compliance with a prescribed treatment is required to achieve the desired improvement in symptoms), research into factors associated with long-term adherence provides important information about what it is that determines whether or not patients continue with treatment in the context of their daily lives, subsequently optimising treatment effectiveness and improving quality of life.

The World Health Organisation (WHO) adopts a multidimensional approach in describing the factors that influence long-term adherence. The five dimensions include healthcare team and system factors, socio-economic factors, treatment-related factors, condition-related factors and patient-related factors [77]. A summary of these dimensions follows.

2.6.1 HEALTHCARE AND SYSTEM FACTORS

Sufficient evidence exists to suggest the patient-provider relationship plays an important role in influencing treatment adherence [79,81]. Although communication is often the focus of research in this area, Palmer (2006) suggests equal importance lies in the ability of the provider to assess the transfer of knowledge to the patient, the development of skills for self-management, and the organisation of appropriate

follow-up care. While clarity of treatment advice has been correlated with short-term adherence, there is little evidence of its significance in improving long-term treatment adherence for chronic conditions [77].

2.6.2 SOCIAL AND ECONOMIC FACTORS

Many long-term treatment strategies come at a significant cost to patients. Not surprisingly, studies of treatment for chronic conditions have identified relationships between poverty, unemployment, illiteracy, and reduced adherence [79]. Associations between non-adherence and other social factors, including race and age, have been reported, but findings have not been conclusive across different settings. The impact of these factors on treatment adherence needs to be evaluated for specific conditions.

2.6.3 CONDITION-RELATED FACTORS

The nature of the health condition and its impact on a patient's daily life are likely to influence adherence. While severe symptoms may require more intensive treatment, they can also make it more difficult to adhere to complex interventions. Symptom severity may influence the patient's perception of risk and their prioritisation of treatment over other demands [77].

2.6.4 PATIENT-RELATED FACTORS

A number of patient-related factors have been identified as influencing adherence to health behaviours [79]. A person's attitudes towards their condition, including their perceived risk of the condition worsening (perceived seriousness), their belief that they have the ability to treat it (self-efficacy), and the values they hold around their health and aspects of their life that are impacted on by the condition, are all likely to influence their motivation to continue complex treatment strategies.

2.6.5 TREATMENT-RELATED FACTORS

Factors that are consistently associated with adherence in the literature concern specific aspects of the treatment program itself [77]. The complexity, time involved, and duration of the treatment period, influence the likelihood that patients will continue to adhere to the treatment as prescribed. A combination of these factors can simultaneously impact on the ability of patients to adhere to treatment, requiring continual assessment of barriers and the development of strategies to address these. This approach recognises the patient as being integral to the adherence process, but

also acknowledges the wider influences on a person's ability to continue with long-term treatments.

2.7 THEORETICAL MODELS IN TREATMENT ADHERENCE RESEARCH

Non-adherence is considered the most important modifiable factor that compromises treatment effectiveness [77]. Research in treatment adherence has involved investigating a range of treatment-, patient- and condition-related factors described above, in many different contexts and settings. While in research settings, extensive efforts may be placed on achieving optimal adherence to interventions (e.g., intensive follow-up of patients), in practice, long-term self-management is dependent on individuals making the decision to continue treatment [81]. Researchers have applied numerous conceptual models in their studies aiming to explain the associations between relevant factors and a patient's likelihood to adhere to treatment [77,79,82].

2.7.1 BIOMEDICAL MODEL

A paternalistic biomedical approach may suggest treatment adherence is a passive process whereby patients follow the directions of the health professional, and success is dependent on patient characteristics (e.g., personality and sociodemographic factors) [77,82]. However, research based on the biomedical approach has failed to identify any particular sociodemographic or individual personality characteristics which differentiate those who adhere to treatment from those who do not [82]. Although this evidence contradicts the main hypothesis of the biomedical model, it has urged consideration of other factors and exploration of their role in influencing adherence behaviour. Findings from this research suggest disease and treatment characteristics have greater influence on whether a patient is likely to adhere, motivating the development of technical solutions to treatment adherence barriers [82].

Interventions aiming to improve adherence based on principles of the biomedical model are often referred to as technical interventions, where steps are taken by health professionals to reduce the demand on the patient. One strategy is the simplification of treatment regimens or programs (i.e., simplifying dosage or packaging of medications), aiming to increase the likelihood of patients complying with prescribed treatment by making it easier to do so. Although many studies of chronic conditions have found this to be effective [83], the evidence indicates over a period of time that the

effectiveness of technical interventions decreases [75], suggesting it may be more appropriate for the treatment of acute conditions than those requiring long term management. Behaviour theorists propose external factors and the cognitive processes of patients (described below in Section 2.7.2) play a significant role in determining health promoting and disease management behaviours, which are largely ignored by the biomedical model [77,82].

2.7.2 PSYCHOSOCIAL MODELS

A number of psychosocial models, including the Health Belief Model (HBM), Theory of Reasoned Action (TRA) and Theory of Planned Behaviour (TPB) present frameworks for further understanding additional factors relating to a person's thoughts, attitudes, and beliefs, and the impact these have on the likelihood of a person performing a particular behaviour [82,84]. Besides knowledge, an individual's thoughts and beliefs about their ability to perform the behaviour (self-efficacy) as well as factors in their environment may influence attitudes towards specific behaviours (e.g., societal or cultural norms, or treatment barriers).

The HBM was developed by a group of social psychologists in the 1950's and is commonly used in the development of health education, health promotion and behavioural interventions [85]. The HBM suggests the likelihood of a person taking action towards addressing a health problem is dependent upon perceived threat and outcome expectations. The level of perceived threat is influenced by perceived susceptibility (i.e., risk of contracting an illness) and perceived seriousness (i.e., consequences of leaving a health problem untreated) of the health problem. The perceived benefits of the behaviour and perceived barriers to taking action combine to form a person's outcome expectations associated with performing a particular behaviour. The model has been used in research on preventive health strategies, diagnosis seeking and screening behaviours, and to explore adherence to prescribed medical treatment. In a review of 46 interventions based on the dimensions of the HBM, "perceived barriers" was the strongest predictor of a range of health behaviours across settings [86]. Despite the successes of interventions designed according to the HBM, the effect size of the behavioural improvements is often small [82]. A limitation of the model in understanding treatment adherence is that the model only assists in understanding the variation in health behaviour attributable to

individuals' attitudes and beliefs. This does not allow for consideration of other influences, such as economic or environmental factors, habitual behaviour and behaviour undertaken for non-health-related reasons [84,86]. In addition, the HBM suggests a person's motivation to engage in a given health behaviour is dependent on their perceptions of their own susceptibility and the seriousness of a health problem. Other behavioural theorists propose there are more factors involved in influencing motivation than these aspects of perceived risk.

Fishbein and Ajzen (1975) argue that social norms also influence motivation, and developed the TRA, and the later extended TPB[87]. The TRA proposes a person's actions are determined by their attitude towards certain behaviours and subjective norms (what it is the individual believes others think they should do, and whether they are motivated to comply). In practice, this model suggests if a person thinks undertaking a particular behaviour will benefit their health and they feel social pressure to do so, they are more likely to intend to and to actually undertake that behaviour. The theory was developed further to the TPB, incorporating perceived behavioural control to the model as an additional influence on behavioural intentions. This aspect of the model is similar to the concept of self-efficacy (a person's belief in their ability to perform a behaviour), proposing that even if a person intends to behave in a particular way, the behavioural intention is only likely to result in the desired behaviour if they believe they have power and control over both intrinsic factors (e.g., problem solving skills) and external factors (e.g., accessibility). However, the TPB appears to be most effective in predicting preventive health behaviours and those with strong social influences, such as smoking and sun protection [85,88]. It is expected the influence of social norms on personal decisions around an individual's medical treatment would be less, and disease- and treatment-related factors not adequately accounted for by this model would have greater impact on treatment adherence.

2.7.3 TRANSTHEORETICAL MODEL

The Transtheoretical model (TTM) was developed by Prochaska and colleagues in an attempt to integrate the field of health behaviour theory, which had fragmented into over 300 theories by the 1980's [89]. The model describes the stages of change people go through when adopting new health behaviours (precontemplation, contemplation,

preparation, action, maintenance). The constructs from the TTM are often combined with constructs from other behavioural models. For example, an intervention may be developed based on the HBM, but taking into account the 'stages of change' of their target population, recognising that the needs of those who are only contemplating changing their behaviour are different from those who are actively engaging in the desired behaviour. An important construct of the TTM is decisional balance, also described as the process of weighing up the pros and cons of changing behaviour. Studies of the TTM across a range of behaviours and settings have found the results from this process shifts as a person moves from one stage to the next (i.e., as a person moves from the contemplation stage to action, the pros of engaging in the behaviour outweigh the cons). This model suggests it is necessary to consider the factors that are perceived by patients as pros and cons of initially undertaking treatment and of continuing treatment long-term, as well as the way individuals weigh the importance of these factors.

2.7.4 DECISIONAL BALANCE MODEL OF TREATMENT SATISFACTION

Research towards a treatment satisfaction tool to be used with patients with varying chronic conditions led to the development of the Decisional Balance Model of Treatment Satisfaction [90]. The study confirmed that two of the three most common dimensions on which patients evaluate their treatment relate to barriers, specifically the side effects of treatment and the convenience of use [90]. The third dimension found to be commonly self-evaluated by patients, and influencing treatment satisfaction, was treatment effectiveness. This model emphasises the importance of understanding the role of patient perceptions when exploring treatment adherence or developing interventions to improve adherence should not be minimised. The value a person places on different treatment attributes is likely to have significant influence on their decision to continue or cease a treatment program [90].

Many other theoretical models have been devised, often with overlapping components, but as yet, no single model appears to be superior to others in explaining treatment adherence. Despite the study of over 200 variables (including sociodemographic and condition-related factors) to determine associations between patient satisfaction and treatment adherence since the 1970's, there have been no conclusive findings regarding the most important predictors of adherent behaviour

[76,80]. Further, successful strategies to overcome barriers to adherence in one particular setting have often been unsuccessful in other settings [82]. Findings from studies investigating patient adherence suggest the fragmentation of research, absence of a single model or theory able to integrate the findings of different studies, and inconsistent definitions of relevant terminology, have delayed understanding, measurement and resolution of non-adherence [75,76]. The slow progress in all areas of this research highlights the complex nature of treatment adherence as a research outcome.

As the prevalence of chronic diseases has increased over the past 50 years, there has been a push for greater reliance on self-management practices and more research into patient satisfaction with health care and medical treatment and services [91]. Despite this, and many attempts at improving adherence with complex interventions, non-adherence rates remain largely unchanged, with medical treatment adherence for some chronic conditions estimated as low as 51% (chronic obstructive pulmonary diseases) and 55% (asthma) [75]. The development of appropriate strategies to improve long-term adherence to treatment for a particular condition first requires an understanding of the factors influencing the patient's ability to commence, and then continue a treatment program.

2.8 ISSUES IN LYMPHOEDEMA MANAGEMENT

Due to the chronic nature of lymphoedema and serious consequences of progressive disease, long-term adherence to interventions which improve lymphatic flow appears necessary to manage lymphoedema effectively [55,57,92–96]. Accessibility of treatment, associated costs and the time and/or discomfort involved with treatment are considered unacceptable to some, potentially influencing adherence and treatment effectiveness [95,97]. The evidence relating to factors influencing lymphoedema treatment adherence is summarised below, categorised according to the five dimensions affecting adherence to long-term therapies defined by the WHO [77].

2.8.1 HEALTHCARE AND SYSTEM FACTORS

Effective lymphoedema management is often dependent on access to appropriate treatment programs within the health care system and the availability of experienced

health professionals. Several issues have been identified as barriers to the provision of effective treatment, including delayed diagnostic and treatment pathways, and limited lymphoedema knowledge and understanding amongst health professionals.

The structure of the health care system influences the duration, cost and availability of lymphoedema treatment. For example, lymphoedema management has never belonged to one specific medical speciality [98], resulting in varied treatment pathways being prescribed by health professionals from different disciplines [3,34]. Over the past decade, multidisciplinary centres have been established to treat lymphoedema, involving dermatologists, surgeons, nurses, physiotherapists, occupational therapists, podiatrists, dieticians and orthotists [98]. A clinical perspective analysis of a multidisciplinary lymphoedema centre reported the benefits of a holistic approach towards treatment include: access to multidisciplinary assessment and standardised diagnostic procedures; combined treatment plans based on knowledge and experience of a range of health professionals; higher continuity of treatment and improved patient satisfaction and compliance; enhanced opportunities for education, training and research; and increased awareness of lymphoedema across disciplines [98]. Although the establishment of such centres requires considerable resources, research into cost-effectiveness indicates the diagnosis and adequate treatment of lymphoedema in its early stage can significantly reduce both direct and indirect costs, compared with treatment for advanced lymphoedema resulting from delayed or missed diagnoses [99]. While the traditional model of impairment-based rehabilitation relies on patients or health professionals recognising symptoms of lymphoedema and seeking appropriate treatment, this approach can result in lymphoedema reaching an advanced stage before treatment is initiated [99]. Findings from an analysis of the costs involved in treating advanced versus early stage lymphoedema have suggested that implementing a surveillance program following cancer treatment to enable early detection and treatment of lymphoedema could reduce total health care costs associated with lymphoedema by more than half [99].

Health professionals have identified a lack of support and training as a barrier to providing treatment. A study exploring knowledge, diagnostic procedures and treatment prescribing practices of health professionals treating lymphoedema in Australia (including physiotherapists, occupational therapists, registered nurses and remedial massage therapists) found that only the minority felt they had received

adequate training from their professional body [41]. Likewise, health professionals involved in a study in the UK felt they did not know how to treat complex wounds and expressed frustration over not always having access to multidisciplinary care, particularly for patients with more advanced lymphoedema and associated complications [100]. While the majority of health professionals in the Australian study indicated they sourced additional information regarding lymphoedema treatment from patient organisations, journal articles, books, postgraduate courses and the internet [41], other studies have identified limited lymphoedema knowledge, inappropriate prescribing practices (e.g., diuretics), and dismissive attitudes towards patients' symptoms as common issues in this setting [3,34,37].

Patients and health professionals identify confusion over treatment advice, and concern and frustration over delayed access to treatment, as barriers to effective lymphoedema management [34,37,101,102]. Health professionals specialising in lymphoedema care in the UK raised a number of concerns about the care of lymphoedema patients within the health care system [100]. They believed the apparent lack of professional knowledge and interest in treating lymphoedema patients, negative views about the likely effectiveness of treatment, and the belief that treating patients with lymphoedema was time consuming and expensive, delayed referral to appropriate services and resulted in patients developing irreversible complications [100].

A lack of understanding amongst health professionals is considered another potential barrier to providing adequate care [3,28,40]. Patients have described dismissive and insensitive attitudes from health professionals [28], including being told "it's nothing", "you have to live with it" or "it will clear up" [37]. Clinicians who trivialise the impact of lymphoedema underestimate the long-term and debilitating nature of the condition [28]. Evidence suggests few patients receive psychological support as part of their treatment, despite clear reductions in quality of life [3], and acknowledgment that psychosocial factors have a significant impact on patient compliance and the provision of effective lymphoedema care [100].

Patients' confusion about treatment can be a result of receiving inconsistent advice from health professionals [65]. Between 25-38% of participants in three different studies felt the lymphoedema information they received was inadequate [37,102,103]. Breast cancer patients gave examples of receiving conflicting advice regarding use of

their arm, with some suggesting they should rest the affected arm and others advising to use the arm as much as possible [65,101]. Professional perceptions that lymphoedema is not painful conflict with patients' reports of lymphoedema symptoms, suggesting a lack of understanding about the patients' experiences of the condition [3]. These issues can negatively influence patient-professional relationships, patients' beliefs about the possibilities for effective treatment [100], and subsequently impact on compliance and treatment effectiveness.

2.8.2 SOCIAL AND ECONOMIC FACTORS

Social and economic factors may impact on patients' likelihood to adhere to long-term treatment, due to the significant cost and complex nature of lymphoedema treatment strategies. The only study directly exploring relationships between social and economic factors and adherence to an intervention aiming to treat lymphoedema, found no significant relationships [104]. However, this study involved participants completing a daily, home-based exercise program, and did not include the more commonly prescribed and costly interventions, such as CPT and compression garments.

The financial burden associated with lymphoedema treatment is considerable, with studies finding the cost of compression garments and consultation fees a concern to a large number of patients [37,41,105,106]. In addition to the direct costs of different treatments, patients often have transport costs and some are required to take leave from work to undergo intensive treatment [100].

Additional social factors found to influence adherence in other settings include age, education level, living arrangements, and levels of social support [77]. Although few studies have explored these factors in the context of lymphoedema management, the following findings suggest more research attention to this issue is warranted. Issues influencing adherence may differ across age groups, with health professionals drawing particular attention to the issues faced by young patients, including dealing with stigma, unattractive compression garments, and intensive treatments which can be intrusive and difficult to schedule in their busy lives [100]. With respect to education levels, patients with higher education levels have been found to experience more fear of using the affected limb [107], and are more likely to express anger over receiving inadequate information, and source their own information about treatment [101].

Living arrangements may influence lymphoedema management in multiple ways. Living location often determines access to health services and availability of health professionals trained in lymphoedema care [106]. Further, those who live alone may have difficulty with self-care, including use of compression garments and skin hygiene [100]. Health professionals specialised in lymphoedema treatment reported associations between poor housing and living alone, and recurrent infections and deterioration of lymphoedema [100]. Level of social support is also suggested to impact on compliance with treatment and levels of psychological distress [108].

2.8.3 CONDITION-RELATED FACTORS

Symptoms of lymphoedema may influence adherence in a number of ways. While physical and psychological difficulties can prevent people from undertaking treatment and unexpected changes in symptoms may cause them to stop treatment, symptoms can also act as a motivator to continue treatment, particularly if the patient fears worsening of their condition [34,65,103,109]. The chronicity of the condition may also influence treatment use, adherence and effectiveness. Patients who experience acute exacerbations may need to alter treatment based on the symptoms they experience at different stages of the condition trajectory.

Research exploring the impact of symptoms on lymphoedema treatment adherence is limited, but suggests lymphoedema severity, location (upper-limb versus lower-limb) and type (cancer related versus non-cancer related) may be related to adherence and treatment effectiveness [34,95,109]. The relationship between symptom severity and adherence is unclear. Severe symptoms may physically prevent patients from completing treatment as prescribed, for example, those with severe swelling may have difficulty applying compression garments, and self-massage can be particularly hard for those with truncal swelling [100,110,111]. Further, there is evidence to suggest those with more severe swelling experience greater fear of activity or movement of the effected limb [107], and that those who experience changes in symptoms following physical activity may withdraw from the activity unless they can be reassured that their lymphoedema is not progressing [65]. However, other studies suggest patients with more lymphoedema symptoms, lower overall quality of life, and those with lymphoedema of longer duration, were more likely to adhere to prescribed treatment

[95,103]. These ambiguous findings highlight the need for greater research attention on the relationship between condition-related factors and adherence.

2.8.4 PATIENT-RELATED FACTORS

Patient-related factors likely to influence adherence to lymphoedema treatment include level of knowledge, attitudes, beliefs and perceptions, relating to both the patients' condition and past illness and treatment experiences. Research suggests knowledge and education are beneficial to patients, increasing their sense of control over their condition and facilitating self-care [79,100,108,110]. However, several studies have described the detrimental impact of providing inadequate information [100,101,112]. Findings suggested patients who received inappropriate advice regarding their lymphoedema, or who had a poor understanding of the prescribed treatment program, were less likely to continue with treatment [100]. Further, patients who felt they had a lack of information or inaccurate information had increased levels of fear, confusion and other negative emotional responses, impacting on decisions regarding arm care and adherence to treatment [101,112].

Patients' attitudes and beliefs about their condition and treatment are likely to play an important role in determining whether they continue long-term treatment. These beliefs may be influenced by previous experiences, the beliefs of family, friends or trusted health professionals, patients' coping mechanisms, and their understanding about lymphoedema and the risk of progression [20,37,79,100,104,107,112,113]. In a study involving breast cancer patients with lymphoedema, some reported concerns about worsening symptoms and complications as motivating them to continue with treatment long-term [20]. Confirming this, several women with LLL following treatment for gynaecological cancers said they were motivated to continue with time-consuming massage and exercise routines if they had seen someone with severe LLL [37]. However, others, described as using more passive coping and avoidance strategies, did not adhere to treatment despite knowing how to manage their swelling, with the hope that the swelling would just 'go away' [113]. It is unclear from the limited research whether factors such as lymphoedema severity or levels of lymphoedema knowledge are associated with patients' perceived seriousness of the condition, but there is suggestion the more the condition is felt to be a threat to life, the greater the urge to treat it [97].

Patients' perceptions of treatment effectiveness reflect the subjective improvements in symptoms following treatment. Evidence suggests those who perceive their treatment to be effective are more likely to continue with it [112]. Further, previous experiences of ineffective treatment are considered to be a major factor influencing treatment adherence [100]. The role of perceived effectiveness in lymphoedema treatment adherence has not been explored adequately, but these findings highlight the importance of considering patients' perceptions in addition to objective measures when investigating treatment effectiveness.

2.8.5 TREATMENT-RELATED FACTORS

The cost, duration and discomfort associated with commonly prescribed lymphoedema treatment strategies can be a significant burden to patients [20,34,114]. It is unclear whether treatments prescribed and administered by health professionals are required on a regular basis to obtain best results or whether intensive periods of treatment (e.g., CPT) followed by self-management strategies are equally effective. Patients commonly undertake a number of different treatments simultaneously [10], which can make it particularly difficult to isolate which are most effective. Patients face many barriers to treatment adherence, whether they are undertaking intensive treatment or long-term maintenance strategies such as self-massage and wearing compression garments.

Undertaking CPT treatment is costly, time-consuming, and can be exhausting and traumatic for patients [20,92,114]. Patients may be required to travel long distances to access treatment, take periods of time off work, and be unavailable to care for family [3,114]. Self-care strategies to manage lymphoedema can also be burdensome to patients and difficult to complete successfully [103]. Studies of the use of compression garments and compression bandaging have found difficulties applying bandages and garments can result in improper use and lower compliance [100,115]. Additional barriers to the long-term use of compression garments include the cost, appearance, discomfort, and difficulties accessing correct-fitting garments [37,79,95,116]. Estimates of adherence to self-care vary widely, with studies reporting 45-97% of participants completing some type of self-care to manage their lymphoedema [37,116]. These ranges apply to different self-care strategies (i.e., compression, massage and exercises), and small sample sizes, varying study designs, and the use of different outcome measures preclude the

drawing of conclusions about whether patients are more likely to continue with any one aspect of self-care.

2.9 SUMMARY AND IMPLICATIONS

Lymphoedema is a chronic and incurable condition, which can have a significant impact on daily activities and quality of life. Evidence of the impact of ULL following breast cancer suggests women can experience a range of physical symptoms, as well as significant psychological impacts, and difficulties with employment, social situations and personal relationships. The review of the impact of LLL on quality of life described in Section 2.2.1 filled a gap in the research, and found those with LLL may experience many of the same adverse effects as those with ULL, with additional challenges identified, particularly with extended use of the lower-limbs (e.g., standing or sitting for long periods) and difficulties with intimacy and sexual function. It is likely lymphoedema would have a similar impact on the quality of life of men, but this area requires further research attention.

People with lymphoedema use a range of mainstream and CAM therapies to treat their condition (described in Section 2.4), with many using a number of treatments concurrently. Reductions in limb volume have been demonstrated following a range of treatments, but the most effective treatments are yet to be clearly identified. Lymphoedema treatment studies to date have assessed the effectiveness of treatment interventions mostly by examining objective patient outcomes (e.g., limb volume reductions), and rarely consider the importance of the patient's subjective response to treatment, the burden of treatment to patients or the impact of non-adherence on treatment success [100,117,118]. This is not uncommon in studies of healthcare quality, which have historically focused on clinical perspectives rather than patient perceptions [119]. In addition, while lymphoedema is a chronic condition, many patients report acute exacerbations (e.g., in hot weather or following long-distance travel), and the treatment needs across different stages of the trajectory are rarely considered in intervention studies. It is plausible that different treatments are effective for different symptoms, and that optimal management of the condition long-term requires use of a range of treatments for some people.

Non-adherence is considered the most important modifiable factor compromising treatment effectiveness [77]. As reviewed in Section 2.7, many health behaviour models

have been applied in research exploring adherence to treatment for chronic conditions. While interventions developed based on the biomedical model have improved adherence to some medical treatments, the success of such interventions appears to decrease over time. This suggests their suitability may be limited for managing chronic conditions which require ongoing commitment for self-care from the patients. On the other hand, behaviour theorists who take into account the cognitive processes largely ignored by the biomedical model, may not adequately consider the impact of economic and environmental factors on patients' ability to adhere to a long-term treatment program.

It is clear that no single model has been identified as predicting adherence across different settings, and that many interrelated factors likely influence treatment use. The following conceptual summary presents the range of factors associated with treatment adherence for lymphoedema, as reviewed in Chapter 2. Factors are grouped according to the domains defined by the WHO, and their relevance to different theoretical models is represented by the symbols, as per the key.

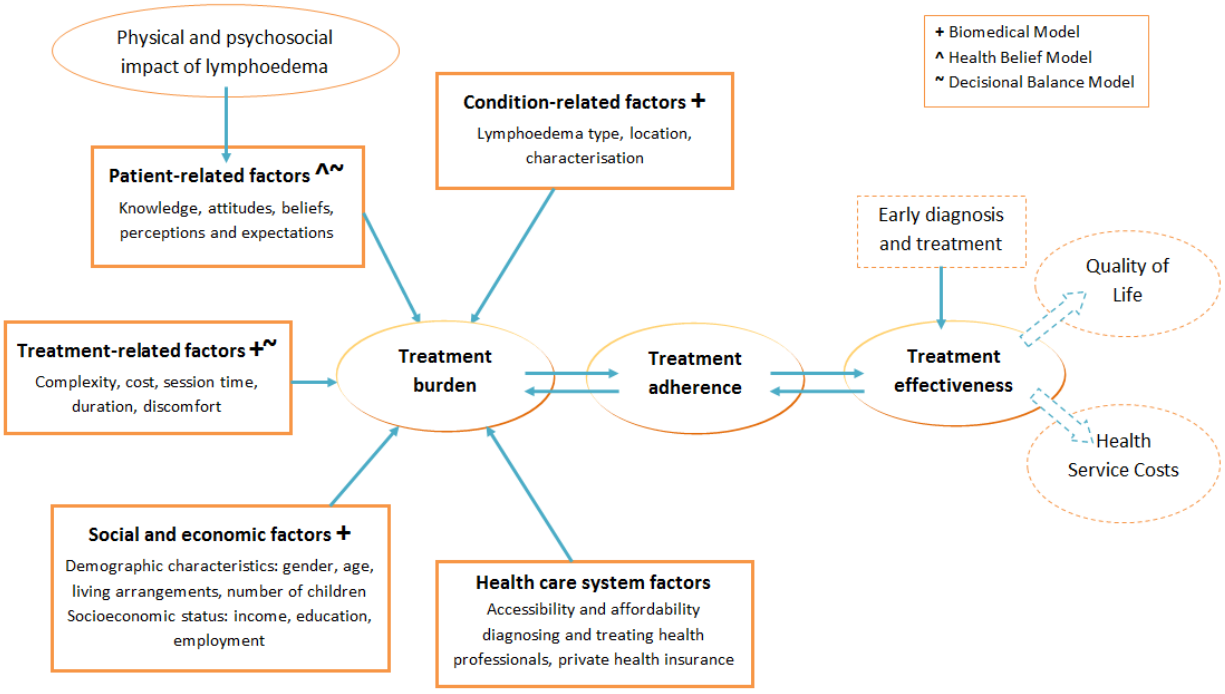

Figure 2.1 Conceptual model of factors influencing treatment adherence and effectiveness

Condition-, treatment- and patient-related factors, as well as social, economic and health care system factors all contribute to the long-term treatment burden. In addition, these factors are likely to be interrelated. For example, a person's

perceptions and expectations of treatment (patient-related factors) may be influenced by the severity of their condition and/or the complexity and cost of treatment (expecting greater effectiveness from more complex or costly treatments). Evidence from treatment adherence for other chronic conditions suggests this treatment burden influences treatment adherence, and subsequently treatment effectiveness, but these relationships have not been explored in any detail in the context of lymphoedema management.

The role of social and economic factors in treatment adherence has differed across different settings. For some conditions, levels of adherence to medical treatment has been associated with poverty, unemployment, illiteracy, race and age [77,79], while for lymphoedema, the only study exploring these associations found sociodemographic factors were not associated with adherence [104]. It is possible the treatment burden is significant regardless of sociodemographic profile. However, considering the only study exploring associations between lymphoedema treatment adherence and demographic factors involved a self-care exercise program and did not include the more costly and complex treatments (e.g., compression garments and MLD), there is a clear need to explore these associations further.

Effective treatment is likely to improve the quality of life of patients and reduce health care costs. Findings from previous lymphoedema treatment research suggest treatment outcomes are optimal when lymphoedema is diagnosed and treated early. However, even when identified early, lymphoedema is considered incurable and requires ongoing management, highlighting the importance of improving treatment adherence. The evidence of treatment effect is building [2] and will be strengthened by future RCTs to confirm the positive findings from previous studies, but there is a lack of attention on the treatment burden and influence this has on long term treatment outcomes. To address this, the third component of this program of research involved designing and conducting a cross-sectional study to explore: the use of treatment by lymphoedema patients and which treatments are most likely to be continued long term; and associations between continued treatment use and condition-, patient-, and treatment-related factors, as well as sociodemographic and health care system factors.

Chapter 3: Research Design

This research used a quantitative approach to investigate the relationships between lymphoedema treatment adherence and range of demographic and psychosocial factors. This chapter details the methods used to address the aim and objectives of the research, describes the stages of questionnaire development, and outlines the procedures used for data collection and data analysis. The ethical considerations of the research are detailed in section 3.6.

3.1 AIM AND OBJECTIVES

The aim, objectives and hypotheses of the third component of this PhD research are as follows:

AIM

To assess the use, acceptability and perceived effectiveness of lymphoedema treatment strategies to people with lymphoedema, in order to explore issues related to lymphoedema treatment adherence.

OBJECTIVES

1. To describe the treatment strategies undertaken by people with lymphoedema, and determine which are continued long term.
2. To describe the clinically relevant level of change in lymphoedema symptoms (by people with lymphoedema).
3. To describe the acceptability of lymphoedema treatment options by people with lymphoedema.
4. To assess the perceived effectiveness of lymphoedema treatment to alleviate the physical symptoms of lymphoedema.
5. To assess the relationships between personal characteristics, lymphoedema characteristics and the use, acceptability and perceived effectiveness of lymphoedema treatment strategies.

$H_{1:}$ There will be differences in the lymphoedema treatment types used by lymphoedema patients with different sociodemographic characteristics.

H_2: There will be differences in the lymphoedema treatment types used by people with different lymphoedema type (primary or secondary), location (region of the body affected) and duration.

H_3: The proportion of people with lymphoedema currently using a particular treatment will be higher for those who find the cost of that treatment acceptable.

H_4: The proportion of people with lymphoedema currently using each treatment will be higher for those who find the time associated with that treatment acceptable.

H_5: The proportion of people with lymphoedema currently using each treatment will be higher for those who find the discomfort associated with that treatment acceptable.

H_6: The proportion of people with lymphoedema currently using each treatment will be higher for those who find the treatment effective for improving their symptoms.

3.2 RESEARCH DESIGN AND METHODS

As treatment adherence has been identified as an important component of overall treatment effectiveness [77], the ideal research design for investigating the significance of adherence in lymphoedema management would involve the addition of adherence measures in longitudinal studies investigating lymphoedema treatments. The benefits of a longitudinal study would include the ability to investigate patterns of treatment use over time, as well as changes in the condition and whether these impact on long-term treatment use. However, due to time and resource limitations it was not possible to adopt this type of design for this study.

Instead, a cross-sectional study of adults diagnosed with lymphoedema was conducted, to explore issues related to adherence for a range of lymphoedema treatments. As part of this research, a participant-administered questionnaire assessed the factors contributing to treatment burden, as detailed below:

- **Condition-related factors**
    - lymphoedema type (primary or secondary; upper-limb, lower-limb or upper- and lower-limb), time since lymphoedema diagnosis, lymphoedema patterns (single episode, recurrent or persistent), and cancer type for those with secondary lymphoedema following cancer.
- **Patient-related factors**
    - perceived effectiveness of treatment options to treat the physical symptoms of lymphoedema;
    - perceived acceptability of the cost, time and discomfort associated with treatment
- **Treatment-related factors**
    - specific treatments undertaken including duration of treatment;
    - cost of undertaking treatment;
    - time involved for treatment sessions;
    - discomfort associated with each treatment; and
    - ability to perform treatment as prescribed
- **Social and economic factors**
    - demographics: age, gender, number of children, income, education level, employment status, living arrangements
- **Health care system factors**
    - health professional who diagnosed lymphoedema;
    - health professional who prescribed treatment; and
    - private health insurance

3.3 DEVELOPMENT OF THE QUESTIONNAIRE – PHASE ONE

The questionnaire was developed in consultation with senior researchers, based on the objectives of this project (see Appendix A). No previously developed tools for the assessment of lymphoedema treatment adherence or satisfaction were identified in the literature.

Due to the lack of evidence in the literature to support the use of one particular model to examine factors influencing treatment adherence [79], research questions were developed based on the conceptual summary of the gaps in the literature (*Figure 3.1*). Although the burden of treatment on patients has been acknowledged in previous lymphoedema research, no studies to date have explored this burden from the patient's perspective. Further, the extent to which the treatment burden influences adherence and treatment effectiveness remains unclear. The aspects of the conceptual summary investigated by the current study are highlighted below (*Figure 3.1*), with variables grouped according to the WHO's five dimensions[77].

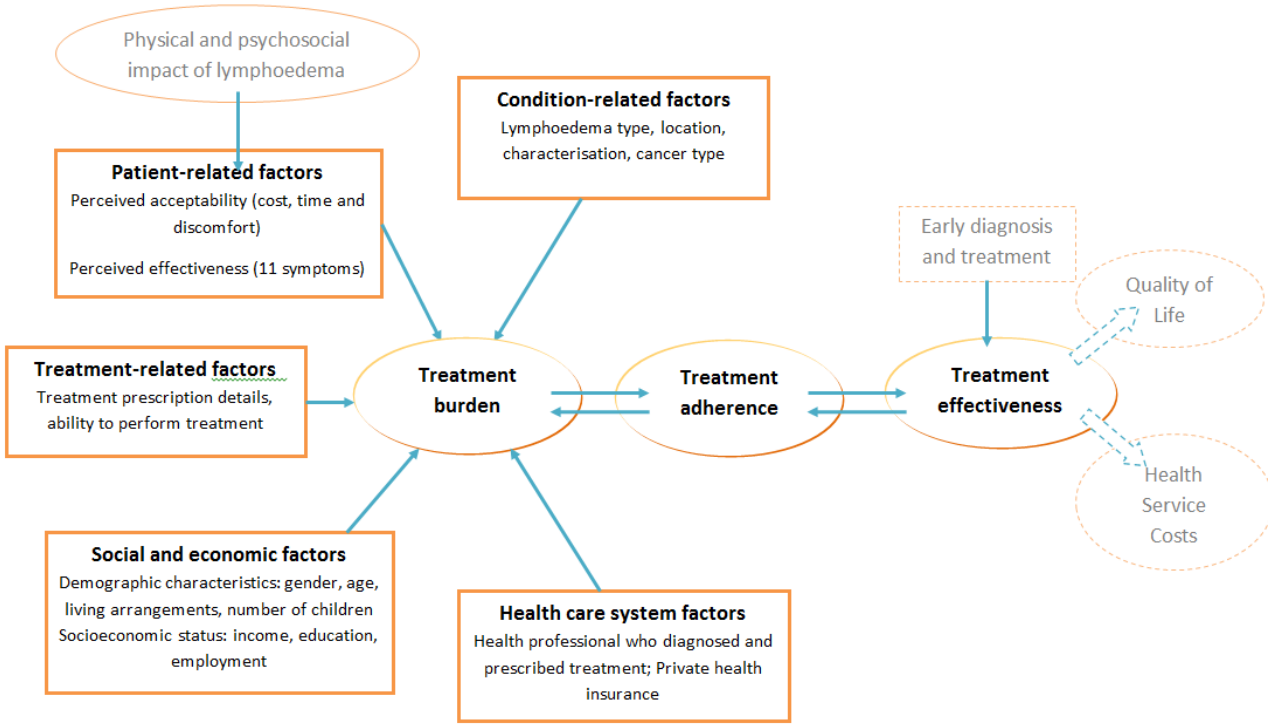

Figure 3.1 Factors in the conceptual summary investigated by the current study

The questionnaire was constructed in 2 phases. Initially, questions were developed to collect information about patients' lymphoedema status, treatments used, and the acceptability and perceived effectiveness of treatments used. Demographic information was collected using questions originally developed for a prospective longitudinal cohort study that included lymphoedema as a primary outcome [120]. Two independent researchers and a physiotherapist reviewed the questionnaire and provided feedback about the face validity of the questionnaire. To improve clarity,

changes were made to incorporate this feedback into the questionnaire. It was determined throughout this process that the most feasible way to collect information on the use, acceptability and effectiveness of treatments was to create a section of the questionnaire for each different treatment type being assessed. This way, only participants who used a particular treatment were required to complete the relevant questions. To further ensure the face validity of the tool, the questionnaire was completed by two women with lymphoedema to determine whether questions were easily understood and interpreted in the way intended by the researcher. The primary change following feedback from these women was further clarification of treatment types (i.e., providing explanations of each treatment type to prevent misunderstandings due to the differing terminology used by health professionals and patients, for example, massage versus MLD).

3.3.1 TREATMENT TYPES

Treatment types explored by the questionnaire included those identified as the most commonly prescribed treatment strategies by health professionals for the management of lymphoedema [41,55], as well as those considered in the literature to be 'mainstream' or 'conventional' treatment options [2,55]. The nine treatment types were defined as CPT, MLD, self-administered massage, laser therapy, pneumatic pumps, compression bandaging, compression garments, prescribed exercises and surgery (defined in Section 2.3.5).

3.3.2 QUESTION TYPES

Forced-choice questions were used to collect information about demographic characteristics (age, gender, marital and parental status, household income, education level, employment status, living arrangements and private health insurance), when applicable cancer type and treatment (surgery, chemotherapy, radiotherapy, hormone therapy), lymphoedema type (upper- or lower-limb, and primary or secondary), the use of lymphoedema treatments (CPT, MLD, self-massage, compression garments, compression bandaging and PCP, laser therapy, exercise, surgery), reasons for discontinued use of treatment, and the need and availability of another person to assist with lymphoedema treatment. Additional questions asked participants to

provide information on characteristics of their lymphoedema (location, duration, diagnostician, persistence of symptoms).

Likert scales were used to measure the acceptability and perceived effectiveness of lymphoedema treatments used by participants, the importance of symptom improvement and the importance of other lymphoedema-related factors (visual appearance, ability to wear normal clothing, improvement in function and mobility). Four aspects of acceptability (cost, time required per treatment session, duration of total treatment period, and discomfort) were measured using a scale labelled 'unacceptable', 'somewhat unacceptable', 'neutral', 'somewhat acceptable' and 'very acceptable'. The Likert scale used to measure how much a treatment helped with a range of lymphoedema-related symptoms was labelled according to 'helpfulness' as 'not at all' , 'very little', 'a little', 'quite a lot', and 'very much', with a 'not applicable' option provided for those who did not experience a particular symptom. The importance of symptom improvement and other related factors to participants were measured with a Likert scale labelled 'not important at all', 'unimportant', 'neutral', 'quite important', and 'very important'.

A seven point rating scale used in a previous study of breast cancer patients was used to ask participants to rate their 'overall health' and 'overall quality of life' during the past week, with one end of the scale labelled 'very poor' and the other 'excellent'.

As this research was informing a broader understanding of the patients' perspectives regarding treatment adherence, limited open questions were asked to enable participants to provide additional information about reasons for discontinuing use of lymphoedema treatments, and the level of change in their lymphoedema that would be considered as an acceptable treatment outcome.

3.3.3 PHASE TWO QUESTIONNAIRE REVIEW

Prior to data collection through Lymphoedema Association of Victoria (LAV), participant responses from 134 questionnaires were reviewed to explore the ways in which people responded to different types of questions and to determine whether the information gained from the questionnaires was suitably addressing the research questions.

A number of changes were made to the questionnaire before further distribution:

- Age requested in years rather than date of birth
- Injury and trauma (as possible causes of lymphoedema) were combined
- Self-administered massage was renamed ‘self-massage’ and treatment descriptions were amended to reflect difficulty participants appeared to have in determining which treatment sections to complete (i.e., if participants completed CPT which included compression bandaging, whether they should also complete the section on compression bandaging separately)
- An open question was added to each treatment section - ‘In your own words, please tell us what this treatment entails (i.e., tell us what was prescribed, how often you attended sessions, how long each session was and the length of the total prescribed treatment period). This modification was made because in the initial data collection, a number of participants had recorded elsewhere on the page what their treatment involved. On review of this information, there were significant differences in what had been prescribed to different patients. The importance of knowing what was involved in the treatment that participants were rating as effective and acceptable was evident.
- Cost was defined as ‘financial cost’ (in question about acceptability)
- Time was divided into two categories (in question about acceptability) – ‘Time required per session/day’ and ‘Duration of total prescribed treatment period’
- Likert scale relating to how much a treatment helped with symptoms was changed to combine ratings that appeared too similar (and were not clinically meaningful). The scale was reduced to three categories of helpfulness “very little/little”, “somewhat/moderately” and “quite a lot/very much”.
- The order of reasons for discontinued use was changed to list ‘no longer needed (treatment was effective)’ as the first reason, being the only positive reason provided as an option. Several participants appeared to not

see it among the more negative reasons provided, providing it as their own reason in an open-ended question.

- An ‘other’ treatment option was included, providing space for participants to list any additional treatment type they had used and complete the same questions to rate the acceptability and perceived effectiveness of that treatment.
- The answer options for questions relating to the need for another person’s help to complete treatment were expanded from ‘yes/no’ to ‘yes, all the time’, ‘yes, sometimes’ and ‘no’.
- Likert scale relating to the importance of a treatment improving particular symptoms had three labels changed – ‘unimportant’ to ‘not very important’, ‘neutral’ to ‘does not bother me’, and ‘quite important’ to ‘important’.
- Height and weight (when diagnosed with lymphoedema, at heaviest since diagnosis, current weight) questions were added.
- A final open-ended question was added to ask for any additional information participants wanted to provide relating to their lymphoedema or treatment use (examples of participant responses are detailed in Appendix B). Many participants from the initial round of data collection provided additional information, indicating a wish to share their own experiences of having lymphoedema and associated treatment.

In addition to these changes, the questionnaire was reformatted as a booklet to make it more readable (due to increased spacing between questions) and more easily completed. The questions relating to each treatment type were presented on two pages (left and right side when the booklet was open), improving the clarity of the format and questionnaire design. This was considered important given the substantial size of the questionnaire, at 30 pages in length. The questionnaire included an introduction to the research project, initial questions regarding background demographic characteristics of participants, questions relating to the research questions, further demographic questions and a final acknowledgement of the participants’ effort in completing the questionnaire.

3.4 METHODOLOGICAL CONSIDERATIONS ASSOCIATED WITH QUESTIONNAIRE CONSTRUCTION

Many cross-sectional studies rely on self-reported measurements using rating scales. The subjective nature of these scales necessitates the need to report the psychometric properties, to demonstrate that the tool is both reliable and valid [121]. The types of reliability and validity to be considered are dependent on the type of measurement tool.

3.4.1 VALIDITY

A tool is considered valid if it is shown to measure what it intends to measure. There are several ways to assess validity, including face, content, criterion-related, and construct validity [122,123]. Determining which should be considered when developing a new tool depends on the measure of interest, the type of tool being developed, and the research context.

Face validity refers to whether a tool appears to be measuring what it is supposed to measure 'on face value'. Experts in the field (i.e., clinicians and other researchers) and clients are typically involved in this consultation process, and their interpretations of the measures are compared with those of the researcher. They may also be asked whether the tool is adequately measuring all aspects of a given concept, to determine content validity [124,125].

Criterion-related validity is further divided into predictive and concurrent validity. Predictive validity refers to how well the results from one tool predict the results of a future measure of the same variable, and concurrent validity involves the comparison of the results to another type of measure taken at the same time point, usually considered the gold-standard tool. Concurrent validity is therefore only considered when there is a pre-existing tool measuring the same construct, most often with the aim of determining whether a given construct can be measured as, or more efficiently.

Construct validity refers to the extent to which the measure reflects the theoretical constructs underpinning the hypothesis, and includes both convergent and discriminant validity. Assessing convergent and discriminant validity involves examining whether the measure is similar to other measures it would be expected to

be similar to (convergent) as well as different from other measures it would be expected to be different from (discriminant). Examining convergent and discriminant validity is another way of determining whether the tool is adequately capturing the measure of interest, without inadvertently including unrelated concepts.

3.4.2 REPEATABILITY

The repeatability or consistency of a measurement tool indicates to what degree the tool is expected to produce the same result if repeated at different time points. Unlike systematic error, where the scores of individuals in a given sample are influenced either positively or negatively (e.g., measurements taken by two different clinicians resulting in one set of observed scores being higher than another), this type of measurement error is random. Repeatability of a tool must be measured using identical administration methods and within a time frame where the health condition would not be expected to change, but allowing enough time so that the participants will have forgotten previous questionnaire responses [123].

Kappa is used to estimate the proportion of agreement beyond that which could occur by chance. In contrast to measuring proportions of agreement between two time points, Kappa accounts for the prevalence of different responses across categories. For categorical variables with three or more possible response categories, using a weighted Kappa takes into account the size of the difference in responses between time points (i.e., weighting cases where a response has moved three categories, compared to responses moving one category from one time point to the next). Kappa values of 0.5 and 0.7 indicate moderate agreement and good agreement, respectively [123].

3.5 VALIDITY AND REPEATABILITY OF THE QUESTIONNAIRE

In this study, the face validity, content validity and repeatability of the questionnaire were investigated, and are described in more detail below.

3.5.1 FACE VALIDITY

As described in Section 3.3, face validity of the questionnaire was ensured through reviews by independent researchers, a physiotherapist and people with lymphoedema. The time taken to complete the questionnaire, appropriateness of questions and

clarity were considered by those reviewing the questionnaire. Participant responses from 134 questionnaires were reviewed to explore the ways in which people responded to different types of questions. Changes made to the questionnaire (see Section 3.3.3) prior to distribution through LAV were reviewed by two researchers and a physiotherapist.

3.5.2 CONTENT VALIDITY

Six participants completed the questionnaire twice, one week apart. To assess content validity, participants were asked three additional questions relating to the questionnaire during the first data collection session. Participants were asked questions relating to the *acceptability* and *effectiveness* of treatment methods, and about the *importance* of improvement in lymphoedema-related factors (i.e., improvement in visual appearance), to determine whether there were any aspects of these concepts they felt were not addressed by the questionnaire (see Appendix C). Additional open-ended questions were used within the questionnaire to provide participants with the opportunity to give further information about reasons for ceasing treatment.

Participants indicated two aspects of 'acceptability' they felt had not been addressed by the questionnaire, those being the 'frequency' of treatment, and unavailability of a particular treatment type in their local area. Two participants described symptoms (one symptom each) that had not been included in the list of symptoms used to assess treatment effectiveness, namely 'pitting' and 'heat in legs'. In terms of the importance of improvements in lymphoedema-related factors, one participant reported the questionnaire did not include "ability to do things I want to do in daily life" [sic], and another responded "normality of tissues and softness of skin". Remaining participants indicated all other factors they felt were important relating to *acceptability*, *effectiveness* or *importance* had been included.

3.5.3 REPEATABILITY

Data from the six participants who repeated the questionnaire were entered into the statistical package, Statistical Package for the Social Sciences (SPSS), Version 18. The limited sample size prevented formal statistical testing of repeatability, but visual inspection of the data suggested question responses were consistent.

There were no clinically significant differences in the responses between time points for the outcome variables of interest. These included the treatment (e.g., have you used compression garments to treat your lymphoedema) and current treatment (e.g., are you currently using this treatment?) variables, acceptability of cost, time, duration and discomfort, and the effectiveness variables relating to each symptom. The responses to the variables relating to the importance of improvement in lymphoedema status were not significantly different between time points. Any changes in Likert scale responses were no more than one category (on a 5 point scale) apart between time points.

3.6 ETHICS

The study was deemed low risk as there was no foreseeable risk of harm or discomfort to participants. No sensitive information was collected. There was still a need however to gain ethical approval as the study gathered new information from participants which may have led to some inconvenience in terms of the time taken to participate in the study. This was minimised by the use of a self-administered questionnaire which could be completed and returned at an appropriate time by participants. Ethics approval was obtained by Queensland University of Technology Human Research Ethics Committee, approval number: 0900000984.

3.7 PARTICIPANTS

Eligible participants were adults aged 18 years and over with lymphoedema. The age range was not limited and there were no exclusions based on cancer or treatment types. Data was collected using a convenience sampling approach (see *Figure 3.2*). Specifically, the initial survey was distributed to:

- people with lymphoedema attending a patient information session at the 22nd Congress of the ISL in Sydney in 2009 (70 questionnaires distributed); and
- members of the Lymphoedema Association of Queensland (LAQ) (n=250) in 2010. LAQ is a self-help organisation offering support, information and education to anyone affected by lymphoedema including those with primary or secondary and ULL or LLL.

The modified survey was distributed to:

- members of the LAV in 2010 (n=710).

To maintain the privacy of LAQ and LAV members, all member details were retrieved and prepared for the mail-out by the respective state association committees. The surveys to LAQ were mailed as a one-off distribution and included instructions to return completed surveys in reply-paid envelopes within two weeks. The method of distribution was reviewed prior to the LAV mail-out, which included a reminder post-card sent 2 weeks after the surveys (see Appendix D). Distribution of the survey through the state-wide lymphoedema associations was the most feasible way of recruiting participants diagnosed with lymphoedema. A limitation of this sampling approach is possible bias introduced by participants being members of the associations; they may be more informed and more likely to be active seekers of treatment than those with lymphoedema in the general population.

Of the 70 questionnaires distributed at ISL, 24 (34%) were returned. No details were known about attendees who did not complete the questionnaire. Of the mail-out distributions through LAQ and LAV, both had similar response rates (44% and 43%, respectively). Respondents who were ineligible for inclusion included health professionals who were members of LAV but did not have the condition, those who had not been formally diagnosed with lymphoedema and parents of children with lymphoedema.

70 questionnaires distributed at ISL patient information session
24 questionnaires returned (34%)

250 questionnaires sent to LAQ members	
8 replied - ineligible	110 (44%) - returned and eligible to participate

710 questionnaires sent to LAV members			
43 replied - ineligible	10- too unwell	8 – wrong address or deceased	307 (43%) – returned and eligible to participate

Figure 3.2 Questionnaire distribution and response rates.

3.8 DATA MANAGEMENT

Data was collected using the mailing lists of the LAQ and the LAV. Questionnaire packages were labelled by members of LAQ and LAV, and member details were not provided to the researcher. Returned questionnaires were allocated a sequential ID number, and hard copies were stored in a locked filing cabinet. Data files were kept on a password-protected personal drive accessible by the researcher only. The initial questionnaire returned by LAQ members and patients attending the ISL patient information session is herein described as the 'first questionnaire', and this cohort described as 'LAQ+'. The 'second questionnaire' refers to the revised questionnaire distributed to, and returned by, members of LAV. This group of participants is described as 'LAV'.

Master copies of both the first and second questionnaires were assigned comprehensive codes, and data was entered into Statistical Package for Social Sciences (SPSS), Version 18.0, by the researcher and a research assistant. After entering data from three of each of the questionnaires, the researcher was consulted to ensure the research assistant was interpreting and entering data correctly (e.g., consistency of data entry when participants had provided a written response instead of ticking one of the boxes provided, or had responded inconsistently). On completion of data entry, a random subset of 10% of the dataset (42 participants, 533 variables) was re-entered for data verification. There were 24 discrepancies noted in 22, 386 variables entered (i.e., 99.89% accurate) so the original data entry was accepted.

3.9 DATA CLEANING

Frequencies were run for all variables and checked against the coding manual to identify any invalid or out-of-range values or inconsistent data (e.g., response "no" to "do you have children?" but a number of "2" in "how many children do you have?"). Where data was missing for a given variable, other related variables were checked and hard copies of questionnaires were accessed, to determine whether data could be entered (i.e. if participants did not answer the question "have you used complex physical therapy to treat your lymphoedema?" but completed all other questions

related to that treatment, it was assumed the participant did the treatment and the response “yes” was entered for the original question).

3.10 VARIABLE DEFINITIONS

The main outcome and independent variables are defined below.

3.10.1 OUTCOME VARIABLES

The main outcome variables for these analyses were use of treatment, current use of treatment, acceptability of treatment, and perceived effectiveness of treatment.

The use of treatment was a dichotomous, categorical variable, defining the number of people who had ever used a particular treatment type. The proportion of people currently undertaking treatment (dichotomous, categorical variable) was also assessed.

Measuring the acceptability of treatment involved multiple outcome variables including, acceptability of financial cost, time involved each session/day, the duration of the total prescribed treatment period, and discomfort. All acceptability variables were ordinal categorical variables, with five levels of acceptability (very acceptable, somewhat acceptable, neutral, somewhat unacceptable, and unacceptable).

Perceived effectiveness of treatment was assessed by participants rating how much each treatment helped to treat symptoms of lymphoedema. The first questionnaire listed 10 different symptoms which were identified from the literature (swelling, heaviness, tightness, aching, tenderness, stiffness, weakness, numbness, pain, and range of movement) and included five levels of effectiveness (not at all, very little, a little, quite a lot, very much). Following review of the questionnaire responses (see section 3.3.3), tingling was added as a symptom and effectiveness was collapsed to three levels, ‘very little/little’, ‘somewhat/moderately’, and ‘quite a lot/very much’.

3.10.2 INDEPENDENT VARIABLES

Objective five explored the impact on these overall results of a range of socio-demographic, condition-related and treatment-related variables. This section considers the transformations of the independent variables from the data collected in the questionnaire, to the variables used in analysis.

Social and economic characteristics

Information about the social and economic characteristics of participants was collected using questions from previous studies involving people with cancer, including those who developed secondary lymphoedema following cancer treatment. Following review of the raw data, some variables were transformed to maximise use of available data, and statistical power for multivariate analysis. Specifically;

- Age was collected to the nearest year, and was retained as a continuous variable. For bivariate analysis, age was recoded into 10 year age groups, then further collapsed to combine groups with too few participants. The resulting four age groups (under 55 years, 55-64 years, 65-74 years, and 75 years and over) enabled comparison of the outcome variables between younger and older age groups.
- Number of children was collapsed into a dichotomous yes/no variable to determine those who had children. The majority of participants in the study were over 55 years and had adult children if any, so the ages of children were not considered relevant for this study.
- Living arrangements were combined to create three categories: living alone; living with a partner, friends or relatives; and other (including nursing home and hostel accommodation).
- Private health insurance was reduced to a yes/no variable.
- Education levels were collapsed from nine original categories to four: year 12 or less; trade or business certificate/apprenticeship; associate or undergraduate diploma; and bachelor degree or higher.
- Household income was collected in $10,000 income levels and was combined according to previous research in socioeconomic status and health outcomes [126]. The income categories used in bivariate and multivariable analyses were <$20,799, $20,800 - $36, 399, $36,400 - $51,999, and >$52,000, with an additional category for those who did not know or did not want to answer the question.

These variable transformations were conducted to improve model stability in multivariate analyses and enable meaningful comparisons between the independent and dependent variables.

Lymphoedema characteristics

Diagnosis of lymphoedema, presence of lymphoedema at the time of completing the questionnaire, lymphoedema type (primary or secondary), and the development of lymphoedema following cancer (yes/no) were collected as dichotomous variables.

Considerable information was collected about the location (right and left side, hand, arm, breast, trunk, leg, foot, and groin), date of diagnosis, diagnosing health professional, duration (>3 months, yes/no) and characterisation (single episode, recurrent, and persistent) of lymphoedema. Following review of the data, location of lymphoedema was collapsed into three categories: upper only (including hand, arm, breast); lower only (including foot, leg, groin); and full body or other (where the parts of the body involved did not fit into either upper only or lower only). Health professionals were recoded as either medical practitioners (including general practitioners and specialists) or allied health professionals, with an additional category for others. The vast majority of participants (79%) had persistent lymphoedema, so those with single episode or recurrent lymphoedema were combined for multivariate analysis.

In addition to lymphoedema characteristics, data were collected about participants' other medical conditions using a standard question from previous research [127]. The question specified 15 medical conditions and provides three answer options: yes, no, and don't know. These variables were combined to create a single comorbidities variable, with five categories ranging from no conditions to 4 or more conditions.

3.10.3 EFFECT MODIFYING VARIABLES

This study included participants with all lymphoedema types and lymphoedema affecting all areas of the body. Review of the literature identified some differences in the impact of lymphoedema between those with ULL and LLL and highlighted potential barriers to treatment specific to lymphoedema location (e.g. requiring help from another person to massage lower-limbs). In addition, available treatment could differ based on the affected region, with those with lymphoedema of the trunk and

groin being unable to apply compression garments. For this reason, results were explored for subgroup differences to determine whether lymphoedema location was an effect modifying variable for the associations between treatment use and other independent variables.

It is recognised that there could also be subgroup differences in other relationships of interest in this study. This particular relationship was explored because of the differences in impact highlighted by the literature review and suggestion in previous research of potential treatment challenges for lymphoedema affecting different regions. It was considered important to explore these differences further and determine whether recommendations should differ based on lymphoedema location.

3.10.4 CONFOUNDING VARIABLES

Many of the independent variables described above in Section 3.10.2 were possible confounders of the relationships between the other independent variables and outcomes explored to address Objective 5. Multivariable regression models were used to adjust for these inter-relationships. The methods for these analyses are described in the Data Analysis section below (see Section 3.12.5).

3.11 STATISTICAL CONSIDERATIONS

3.11.1 CLINICAL IMPORTANCE

The clinical importance of the results was considered in addition to statistical significance. At the bivariate level, results for the use, acceptability and effectiveness were considered clinically important if there was ≥ 10% difference between groups. For multivariable analyses, odds ratios (OR) ≤ 0.5 or ≥ 2.0 were considered clinically important.

3.11.2 SAMPLE SIZE

The sample size required to compare proportions for research question five was calculated using the two proportions equation [128]. To be able to detect a 10% difference between groups with 80% power and a significance level of 5%, where 50% of the referent group had the outcome of interest (e.g., 50% of those with secondary lymphoedema using MLD compared with 60% with primary lymphoedema), it was calculated that 195 participants would be required in each

group. Actual proportions of lymphoedema patients using different types of treatments differed widely, so sample size calculations were based on the assumption that at least 50% of the sample would be expected to have used the treatments reported by health professionals as most commonly prescribed. Statistical power was limited for outcomes related to treatments less commonly used by participants.

3.11.3 ASSUMPTIONS OF TESTS AND MODELS

Prior to conducting bivariate and multivariable analyses, the relevant assumptions were tested.

The distributions of continuous variables are assessed for normality to ensure appropriate summary statistics are used. The only continuous independent variable was age, which was assessed for normality using the following criteria:

- mean within 10% of median;
- mean ± three standard deviations approximates the minimum and maximum values observed;
- skewness and kurtosis coefficients within ± 3; and
- histogram approximately symmetrical and bell-shaped.

The distribution of age did not meet the above criteria, so results are expressed as medians with minimum and maximum values.

The chi-square test for the comparison of proportions within categorical variables assumes the following:

- observations are independent;
- categories are mutually exclusive; and
- all expected cell counts are five or more.

An expected cell count of over five is considered a conservative rule [129], and as such, an expected cell count of over two was used for this analysis. The study was a cross-sectional study with no repeated measures, and study participants were unlikely to be related. Therefore, observations were considered to be independent. For all variables, care was taken during the questionnaire design stage to ensure categories were mutually exclusive and exhaustive.

The absence of collinearity is assumed for logistic regression. It was considered possible that some of the independent variables were measuring the same or very similar concepts. These variables were tested for collinearity to determine the degree of redundancy prior to multivariable modelling. Correlations between variables measured on Likert scales were examined using Pearson's correlation coefficient. Categorical variables suspected to be measuring similar concepts (ie. characterisation of lymphoedema and duration of lymphoedema) were checked at the bivariate level using cross-tabulations of counts and percentages, to consider the similarity of the variables qualitatively. The phi coefficient for 2x2 tables, Cramer's V for nominal variables with 3 or more categories, and Kendall's Tau-b (τb) for ordinal variables were used to statistically test collinearity. If the correlation was above 0.7 or below -0.7, variables were entered into the model separately to assess the change in estimates, as recommended by Tabachnick and Fidell [130]. If the correlation was above 0.9 or below -0.9, the variables were considered to be measuring the same concept.

The following rationale describes the variables tested for collinearity. Lymphoedema duration and characterisation were likely to be strongly correlated (i.e. a high proportion who had lymphoedema for more than 3 months were likely to describe their lymphoedema as 'persistent') so these variables were tested for their degree of redundancy. Household income, employment status and education level are all measures of socioeconomic status. Although these variables are usually considered independent, they often have an effect on one another [126]. For example, education level influences employment status and both variables influence household income. As measuring the acceptability of the cost of treatment was an important part of this research and could be influenced by socioeconomic status, it was important to determine the strength of association between these variables.

It was considered possible the 'treatment effectiveness' variables (for a range of symptoms) could be highly correlated and measuring the same concept. The same was possible for 'acceptability' variables. Although the questionnaire asked participants to rate the effectiveness and acceptability of different aspects of treatment, these variables were tested to determine whether they would need to be entered into separate models due to collinearity.

3.12 ANALYSIS

3.12.1 DATA ANALYSIS – LYMPHOEDEMA TREATMENT USE

Determine which treatment strategies are undertaken by people with lymphoedema, and which are continued long term.

Frequencies and proportions of participants who reported using each treatment were calculated and reported. The second questionnaire included a question asking participants to describe what each treatment entailed. Responses were coded according to whether or not the participant's description matched the definition of each treatment used for this study (see Table 3.1).

Table 3.1

Treatment types and description of treatments

Treatment	Description
Complex Physical Therapy	a period of intensive treatment, or a treatment program involving at least two of the following; MLD, massage, compression bandaging, prescribed exercises
Manual Lymphatic Drainage	session times with a health professional of the procedure of massage techniques used to drain lymphatic fluid
Self-massage	massaging of self or by another person (e.g., partner, NOT health professional) or the time/how often massage was undertaken.
Laser therapy	description of laser machine or how often sessions were attended.
Pneumatic pumps	description of pump, brand, or sessions attended
Compression bandaging	description of bandaging technique or type of bandage
Compression garments	description of garment, stocking, brand of compression garments, or an activity/time

	period in which CG are commonly prescribed (i.e., for air travel).
Prescribed exercises	physical activity program or limb exercises or a source (i.e., brochure) where participant obtained details of appropriate exercises
Surgery	surgical procedure used to treat lymphoedema or associated complications

These data were used to calculate the proportions of participants using each treatment whose description met the defined criteria. If the description met the criteria for another treatment type and no information had been provided for that treatment, the data was moved to its more appropriate treatment type (i.e., if the participant had completed questions in MLD but described performing the massage themselves, data was moved to self-massage). The range of responses provided for each treatment was assessed and examples are provided in the results. However, for all further analyses, all participants who indicated they had used each treatment were included in the analyses. The frequencies and proportions of participants who were currently using each treatment were also calculated and reported.

Participants who did not continue with a particular treatment were asked to indicate the reasons for stopping. On the first questionnaire, seven possible reasons were listed, and an open question was included for participants to respond with additional reasons. After reviewing responses to the open question, an eighth reason for stopping (stopped due to side effects) was included in the second questionnaire. Frequencies and proportions of participants indicating each reason for stopping were calculated and reported for each treatment type.

3.12.2 DATA ANALYSIS – IMPORTANCE OF IMPROVEMENT IN LYMPHOEDEMA STATUS

To describe what level of change in lymphoedema status is perceived as important by people with lymphoedema.

The importance of improvement in physical symptoms was assessed using 5 categories (“not important at all”, “not very important”, “does not bother me”,

"important" and "very important"). The number of participants who had each symptom was calculated by using responses to either questions on effectiveness or importance of improvement in symptoms. As importance was the outcome of interest, proportions of participants who had the symptom and indicated improvement in that symptom was either "important" or "very important" were calculated and presented.

Other factors related to lymphoedema status were considered for their importance to participants, including improvement in visual appearance, ability to wear normal clothing, improvement in function and improvement in mobility. Frequencies and proportions of participants responding "quite important" or "very important" were calculated.

3.12.3 DATA ANALYSIS – ACCEPTABILITY OF TREATMENT

To describe the acceptability of lymphoedema treatment options by people with lymphoedema.

Acceptability of the cost, time, duration and discomfort were assessed for each treatment. The number and proportion of participants indicating each response (5 categories – "unacceptable" "somewhat unacceptable" "neutral" "somewhat acceptable" or "very acceptable") were calculated.

3.12.4 DATA ANALYSIS – PERCEIVED EFFECTIVENESS OF TREATMENT

To assess the perceived effectiveness of lymphoedema treatment, to treat the physical symptoms of lymphoedema.

The proportions of participants with each symptom who indicated each treatment was effective "quite a lot/very much" for that symptom were calculated and reported.

3.12.5 DATA ANALYSIS – FACTORS INFLUENCING TREATMENT USE

To assess the relationships between personal characteristics, lymphoedema characteristics and the use, acceptability and perceived effectiveness of lymphoedema treatment strategies.

Bivariate Analyses

Bivariate analyses were conducted to determine whether any personal/demographic or lymphoedema characteristics were crudely associated with each of the outcome variables (use, current use, acceptability and perceived effectiveness). This was done using crosstabulations and chi squared tests, as all variables were independent categorical variables.

Impact of lymphoedema location on bivariate analyses

Lymphoedema location was considered a possible confounder and/or effect modifier of the relationships between the independent variables and outcomes of interest. Firstly, bivariate analysis was used to assess relationships between lymphoedema location and outcome variables. Confounding variables are associated with both the independent and outcome variable and cause a shift in the results. After establishing associations with outcome variables, lymphoedema location was tested for associations with all independent variables, using crosstabulations of counts and percentages, and chi squared tests of association.

Crude relationships between independent variables and treatment use variables were stratified by the potential effect modifying variable 'lymphoedema location' to establish whether the pattern of association was different within subgroups. When stratified crosstabulations revealed subgroup differences, effect modification was documented. Differences in independent variables with less than 20 cases were not documented due to the resulting oversensitivity.

Multivariable analyses

Binary logistic regression analyses were used to assess the adjusted relationships between personal and lymphoedema characteristics and the use of treatment, as well as the current use of treatment. Four treatment types had insufficient sample sizes to undertake multivariable analyses. Included treatments in multivariable analyses were compression garments, self-administered massage, prescribed exercises, MLD, compression bandaging and CPT. OR and 95% confidence intervals were generated to identify which characteristics influenced the use of treatment.

Two thematic blocks were defined and entered into the model separately. All models included age, due to the known association between age and many health-related outcomes. If variables were found to be related (e.g., education and income), they

were removed and entered one at a time to examine changes in effect size indicative of confounding. The categories of variables with the highest number of participants or the most clinical relevance were defined as the referent groups. Where variables had over 10% missing data, a 'missing' category was defined and included.

Table 3.2

Modelling blocks defined for logistic regression analyses

Block	Variables
Block 1 – Personal characteristics	age, gender, children, living arrangement, private health insurance, education level, employment, income
Block 2 – Lymphoedema characteristics	age, lymphoedema type, lymphoedema location, lymphoedema after cancer, characterisation of lymphoedema, duration, co-morbidities, diagnosing health professional

To prevent exclusion of potentially important variables, those with p-values <0.25 and/or considered clinically important were retained for the hybrid models [131]. Final models included any variables found to be statistically significant ($p<0.05$) or clinically significant (OR <0.5 or >2.0) in the hybrid models. Model fit was assessed using the Omnibus Tests of Model Coefficients ($p<0.05$ indicating independent variables in Block 1 were better predictors of the outcome than Block 0, where it is assumed all participants respond in the way the majority respond to the dependent variable) and Hosmer and Lemeshow Test ($p>0.05$ indicating support for the model). The Cox and Snell, and Nagelkerke R square values were used to assess the amount of variation in the outcome explained by each model, with the values between 0 and 1 suggesting the percentage of variability explained by the variables in the model [132,133].

Chapter 4: Results

This chapter presents the results relating to each objective outlined in Section 3.1. Key characteristics of the sample are described first, providing details of participants from the first and second stages of recruitment to enable comparison of the two groups. Descriptive results are presented to address the objectives related to the use, importance of improvement in lymphoedema, acceptability of treatment, and perceived effectiveness of treatment. Finally, the results from the multivariable models testing the associations between acceptability, effectiveness and current treatment use, are presented for compression garments, self-administered massage, prescribed exercises, MLD, compression bandaging and CPT.

4.1 SAMPLE CHARACTERISTICS

The demographic and lymphoedema characteristics of the 133 eligible participants who responded to the initial questionnaire (the majority from Queensland, who will be referred to as LAQ) were compared with those of the 288 participants who completed the final questionnaire (LAV). There were no significant differences between LAQ and LAV participants for age, gender, child responsibilities, living arrangements, private health insurance status, education level, or household income (see Table 4.1). The majority of participants in both LAQ and LAV groups (82% and 86%, respectively) were aged 55 years or older, with a median age of 66.0 years (min=18.0, max=91.0), and most participants (95% in both groups) were female. Approximately half of the participants in both groups lived with partners, friends or relatives (49% LAQ and 53% LAV), and around 10% had children living at home (14% LAQ and 11% LAV). Education levels were consistent between groups, with around 40% finishing Year 12 or less, 20% completing TAFE or diploma level qualifications, and 27% completing bachelor (or higher) degrees and the majority of participants had private health insurance (77% in both groups).

The majority of participants had secondary lymphoedema (84% LAQ and 76% LAV) and of these, most had developed lymphoedema following cancer treatment (86%

LAQ and 81% LAV). Proportions of participants diagnosed with different cancer types were similar in both LAQ and LAV groups, at 68% and 70% for breast cancer, 15% and 16% for gynaecological cancers, and 16% and 13% diagnosed with other cancers, respectively. The vast majority (96%) had surgical treatment for cancer, around one third had also received radiation treatment, and one third had received both radiation and chemotherapy. One in four participants who had been diagnosed with cancer received hormone therapy.

Participants from LAQ and LAV were similar for lymphoedema location, duration and characteristics. Of the 45% with ULL, 43% (45% LAQ and 42% LAV) had unilateral ULL, and 2% (4% LAQ and 2% LAV) had bilateral ULL. The proportions of those with unilateral and bilateral lymphoedema were more evenly spread for those with LLL, with 21% with unilateral LLL (23% LAQ and 21% LAV) and 22% with bilateral LLL (19% LAQ and 24% LAV). A further 5% of participants had full body lymphoedema, and 6% had lymphoedema in another area of the body (i.e., affected areas of the body did not fit any of the descriptions above). The majority of participants had lymphoedema for more than 3 months (84% of all participants, 79% LAQ and and 87% LAV), and described their lymphoedema as ‘persistent’ (78% of all participants, 80% LAQ and 78% LAV).

Over half of the study participants had two or more other medical conditions (60% total, 59% LAQ and 60% LAQ), with around 20% reporting four or more conditions. Participants’ rating of their overall health and quality of life (on a scale of one to seven, with one labelled ‘very poor’ and seven labelled ‘excellent’) did not differ between groups, with a median overall health rating of 5.0 (min=1, max=7) and median overall quality of life rating of 5.0 (min=1, max=7). The majority rated their overall health and quality of life between 5.0 and 7.0 on the 7 point rating scale (68% and 70.5%, respectively).

Considering the similarities between the samples, participants were considered representative of Lymphoedema Association members in Australia, and it was considered appropriate to pool the data for all further analyses.

Table 4.1

Sociodemographic and lymphoedema characteristics of all eligible study participants

	Queensland		Victoria		Total	
Age median (min,max)	65.0	28.0, 86.0	67.0	18.0, 91.0	66.0	18.0, 91.0
	n	(%)	n	(%)	n	(%)
Age Group						
Under 55 years	24	(18.0)	38	(13.2)	62	(14.7)
55-64 years	37	(27.8)	85	(29.5)	122	(29.0)
65-74 years	44	(33.1)	105	(36.5)	149	(35.4)
75 and over/missing	28	(21.1)	60	(20.8)	88	(20.9)
Gender						
Female	126	(94.7)	273	(94.8)	399	(94.8)
Male	7	(5.3)	15	(5.2)	22	(5.2)
Children						
None	34	(25.6)	67	(23.3)	101	(24.0)
Children under 14 years	6	(4.5)	10	(3.5)	16	(3.8)
Children over 14 years	80	(60.2)	160	(55.6)	240	(57.0)
Children of unknown ages	16	(12.0)	55	(19.1)	71	(16.9)
Children living with you	19	(14.3)	33	(11.5)	52	(12.4)
Living arrangement						
Living alone	44	(33.1)	69	(24.0)	113	(26.8)
Living with partner/friends/relatives	65	(48.9)	154	(53.5)	219	(52.0)
Couple living with children	17	(12.8)	36	(12.5)	53	(12.6)
Other/Missing	7	(5.3)	29	(10.0)	36	(8.6)
Private health insurance						
No	30	(22.6)	48	(16.7)	78	(18.5)
Yes, hospital only	14	(10.5)	50	(17.4)	64	(15.2)
Yes, extras only	5	(3.8)	10	(3.5)	15	(3.6)
Yes, hospital and extras	83	(62.4)	163	(56.6)	246	(58.4)
DVA card	-	-	2	(0.7)	2	(0.5)
Missing	1	(0.8)	15	(5.2)	16	(3.8)
Highest education qualification						
Year 12 or less	54	(40.6)	120	(41.7)	174	(41.3)
Trade or business cert/ Apprenticeship	14	(10.5)	32	(11.1)	46	(10.9)
Associate or Undergrad diploma	17	(12.8)	25	(8.7)	42	(10.0)
Bachelor degree or higher	36	(27.1)	80	(27.8)	116	(27.6)
Other/Missing	12	(9.0)	31	(10.8)	43	(10.2)
Household income						
<$20 799	24	(18.0)	45	(15.6)	69	(16.4)

$20 800 – 36 399	21	(15.8)	40	(13.9)	61	(14.5)
$36 400 – 51 999	24	(18.0)	31	(10.8)	55	(13.1)
$52 000+	31	(23.3)	55	(19.1)	86	(20.4)
Do not know/Do not want to answer question/Missing	33	(24.8)	117	(40.6)	150	(35.6)
Lymphoedema type						
Primary	22	(16.5)	70	(24.3)	92	(21.9)
Secondary	111	(83.5)	218	(75.7)	329	(78.1)
Secondary lymphoedema followed cancer						
Yes	91	(82.0)	177	(81.2)	272	(82.7)
Diagnosed with cancer						
Yes	92	(69.2)	184	(63.9)	276	(65.6)
Cancer type						
Breast	63	(68.5)	130	(70.7)	193	(69.9)
Gynecological	14	(15.2)	30	(16.3)	44	(15.9)
Other	15	(16.3)	24	(13.0)	39	(14.1)
Cancer treatment						
Surgery	90	(97.8)	176	(95.7)	266	(96.4)
Chemotherapy[a] (noradiation)	5	(5.4)	21	(11.4)	26	(9.4)
Radiation[b]	34	(37.0)	59	(32.1)	93	(33.7)
Chemo and radiation	28	(30.4)	59	(32.1)	87	(31.5)
Hormone therapy	27	(29.3)	47	(25.5)	74	(26.8)
Other treatment	12	(13.0)	15	(8.2)	27	(9.8)
Lymphoedema location						
Unilateral Upper	60	(45.1)	122	(42.4)	182	(43.2)
Unilateral Lower	30	(22.6)	60	(20.8)	90	(21.4)
Bilateral Upper	5	(3.8)	5	(1.7)	10	(2.4)
Bilateral Lower	25	(18.8)	69	(24.0)	94	(22.3)
Full Body	5	(3.8)	16	(5.6)	21	(5.0)
Other	8	(6.0)	16	(5.6)	24	(5.7)
Diagnosing health professional						
Medical practitioner	85	(63.9)	186	(64.6)	271	(64.4)
Allied health	27	(20.3)	46	(16.0)	73	(17.3)
Massage Therapist	4	(3.0)	9	(3.1)	13	(3.1)
Other (self, family)	4	(3.0)	13	(4.5)	17	(4.0)
Missing	13	(9.8)	34	(11.8)	47	(11.2)
Lymphoedema for >3 months						
Yes	105	(79.0)	249	(86.5)	354	(84.1)
Lymphoedema characterised						
Single episode	3	(2.2)	2	(0.7)	5	(1.2)
Recurrent	10	(7.5)	26	(9.0)	36	(8.6)
Persistent	107	(80.5)	224	(77.8)	331	(78.6)
Missing	13	(9.8)	36	(12.5)	49	(11.6)
Current lymphoedema						

Yes	126	(94.7)	273	(94.8)	399	(94.8)
Medical conditions[c]						
0	17	(12.8)	47	(16.3)	64	(15.2)
1	37	(27.8)	67	(23.3)	104	(24.7)
2	33	(24.8)	68	(23.6)	101	(24.0)
3	19	(14.3)	39	(13.5)	58	(13.8)
4 or more	27	(20.3)	67	(23.3)	94	(22.3)
Health and QoL[d]	medi	min, max	median	min, max	median	min, max
Overall health rating	5.0	1.0, 7.0	5.0	1.0, 7.0	5.0	1.0, 7.0
Overall QoL rating	5.0	1.0, 7.0	5.0	1.0, 7.0	5.0	1.0, 7.0

[a]Chemotherapy without radiation; [b] Radiation without chemotherapy; [c] Includes: heart attack, angina, high blood pressure, high cholesterol, other heart condition, stroke, diabetes, asthma, chronic bronchitis, emphysema of the lungs, stomach or duodenal ulcer, migraine headaches, osteoporosis, rheumatoid arthritis, depression; [d]measured using a 7-point visual analogue scale; QoL: Quality of life

4.2 OBJECTIVE ONE – LYMPHOEDEMA TREATMENT USE

Determine which treatment strategies are undertaken by people with lymphoedema, and which are continued long term.

At least two thirds of participants had used compression garments (86%), self-massage (79%), prescribed exercises (69%), or MLD (67%) to treat their lymphoedema (see Table 4.2). In addition, compression bandaging and CPT were used by 45% and 42% of participants, respectively. Between 3 to 18% had used laser therapy, PCP, and/or had surgery to treat their lymphoedema (18%, 12%, 3%, respectively), while less than 3% had used a range of other treatments, including whole body exercise, medication, CAM therapies, and electrotherapy.

Over half (62%) of all participants had used more than four lymphoedema treatment types, while 5% had used only one type of lymphoedema treatment. Of those who had only used one or two treatment types (n=70), over half had used compression garments (61%), and at least one quarter had used self-massage (31%), MLD (30%) and prescribed exercises (24%). In this group (using one or two treatments), fewer participants had used bandaging (11%), CPT (7%), surgery (1%), and no participants had used laser or PCP. Participants' descriptions of treatments varied (see Appendix E for examples of treatment descriptions). The defined criteria matched participants' descriptions more often for some treatments (e.g., compression garments and laser therapy) than others (e.g., CPT) (see Table 4.2).

Patients' continued use of treatment varied widely across treatment types. Over three quarters (79%) of the participants who had ever used compression garments were currently using them at the time of the study. Over half of the participants who used self-massage (68%), prescribed exercises (64%) and MLD (58%) reported current use, while less than half were currently using laser (43%), and around one third were currently using CPT and/or bandaging (32% and 30%, respectively). Of note, over a quarter of all participants (27%) reported current use of more than four treatment types, at the time of the study. Similar proportions reported current use of three treatments (20%), two treatments (21%) or a single treatment (22%), and 11% were not currently using any treatment. Of those who reported current use of more than

four treatments, the majority were using compression garments (93%), self-administered massage (92%), prescribed exercises (83%) and/or MLD (80%).

Table 4.2

Use of lymphoedema treatments by all study participants

	Used treatment		Among those who used treatment, proportion whose description met defined criteria		Among those who used treatment, proportion who currently used treatment	
	n	(%)	n	(%)	n	(%)
Complex Physical Therapy	176	(41.8)	62	(63.2)	57	(32.4)
Manual Lymphatic Drainage	285	(67.3)	143	(78.6)	166	(58.0)
Self-massage	332	(78.9)	173	(79.0)	227	(68.4)
Laser Therapy	77	(18.3)	29	(90.6)	33	(42.9)
Pneumatic Pumps	51	(12.1)	11	(73.3)	6	(11.8)
Compression bandaging	188	(44.7)	81	(78.6)	57	(30.3)
Compression garment	362	(86.0)	214	(90.3)	284	(78.5)
Prescribed exercises	291	(69.1)	-	-	185	(63.6)
Specific LE exercises	-	-	153	(77.3)	-	-
Whole body exercise	-	-	17	(8.6)	-	-
Surgery	14	(3.3)	5	(50.0)	-	-
Other[a]	38	(9.0)	-	-	-	-
Whole body exercise	11	(2.6)	-	-	-	-
Medication	6	(1.4)	-	-	-	-
CAM	9	(2.1)	-	-	-	-
Massage	2	(0.4)	-	-	-	-
Body flow	5	(1.1)	-	-	-	-
Specific LE exercises	4	(1.0)	-	-	-	-

[a] Other treatment questions only included in second questionnaire (LAV) and definitions not provided; LE: lymphoedema, CAM: complementary and alternative medicine

4.3 OBJECTIVE TWO – IMPORTANCE OF CHANGE IN LYMPHOEDEMA STATUS

Describe what level of change in lymphoedema status is perceived as important by people with lymphoedema.

Participants reported improvements in physical symptoms following treatment were important in order for them to continue use of a particular treatment. Of the 15 lymphoedema-associated symptoms, more than 60% of those with swelling, heaviness, tightness and reduced range of movement reported improvements in those symptoms as very important. Further, 64% of all participants said improved function of the affected limb was very important. No less than 40% of participants who had each symptom said improvements in that symptom were very important outcomes of treatment.

Table 4.3

Importance of improvement in lymphoedema symptoms

Symptom	n[a]	Very important n (%)	Important n (%)	Not important[b] n (%)
Swelling	418	301 (72.0)	83 (19.9)	37 (8.1)
Heaviness	375	236 (62.9)	93 (24.8)	92 (12.3)
Tightness	375	225 (60.0)	97 (25.9)	99 (14.1)
Aching	323	183 (56.7)	88 (27.2)	150 (16.1)
Tenderness	286	140 (49.0)	76 (26.6)	205 (24.5)
Stiffness	261	134 (51.3)	71 (27.2)	216 (21.5)
Weakness	254	112 (44.1)	67 (26.4)	242 (29.5)
Numbness	225	101 (44.9)	56 (24.9)	264 (30.2)
Tingling[c]	143	57 (39.9)	43 (30.1)	188 (30.1)
Pain	275	157 (57.1)	68 (24.7)	196 (18.2)
Range of movement	328	209 (63.7)	68 (20.7)	144 (15.5)
Improved visual appearance	421	181 (43.0)	129 (30.6)	111 (26.4)
Able to wear normal clothing	421	220 (52.3)	123 (29.2)	78 (18.5)

Improved function	421	268 (63.7)	102 (24.2)	51 (12.1)
Improved mobility	421	170 (59.0)	70 (24.3)	48 (16.7)

[a]number of participants with symptom; all participants (n=421) were asked questions related to factors below the dotted line.
[b]not important includes those who responded 'does not bother me', 'not applicable' or missing.
[c]Tingling only included on second questionnaire – total 288 LAV participants

4.4 OBJECTIVE THREE – ACCEPTABILITY OF TREATMENT

Describe the acceptability of lymphoedema treatment options by people with lymphoedema.

4.4.1 ACCEPTABILITY OF COST, TIME AND DISCOMFORT

At least half of the participants who used compression garments (57%) or surgery (50%) to treat their lymphoedema found the associated financial costs unacceptable (see Appendix F for descriptive results). Between 25 and 40% reported the cost of MLD, CPT, compression bandaging, and laser therapy as unacceptable (36%, 34%, 30% and 28%, respectively), while less than 20% found the cost of PCP (16%), prescribed exercises (5%) and self-administered massage (4%) unacceptable.

One in five participants found the time associated with each treatment session for compression bandaging, PCP and CPT, unacceptable (20%, 22% and 27%, respectively). Between 10 and 20% reported the time involved in using compression garments (17%), prescribed exercises (16%), self-administered massage (16%), MLD (12%) and laser therapy (12%) as unacceptable (see Appendix F).

The duration of the total treatment period was reported as unacceptable by 20 to 25% of participants who used compression bandaging, garments, laser therapy, and CPT (25%, 22%, 22% and 21%, respectively). Between 7 and 18% of participants who used MLD (18%), self-administered massage (14%), prescribed exercises (13%) and PCP (7%) found the duration of the prescribed treatment period unacceptable (see Appendix F).

About half of the participants (57%, n=8) who had surgery to treat lymphoedema found the discomfort unacceptable (see Appendix F). Around one in three

participants who used compression bandaging (36%) and garments (31%) reported the discomfort as unacceptable. The discomfort associated with CPT was unacceptable to 21% of participants, while less than 10% of those who used PCP, prescribed exercises, MLD, self-administered massage or laser therapy reported unacceptable discomfort (10%, 7%, 5%, 5% and 5%, respectively).

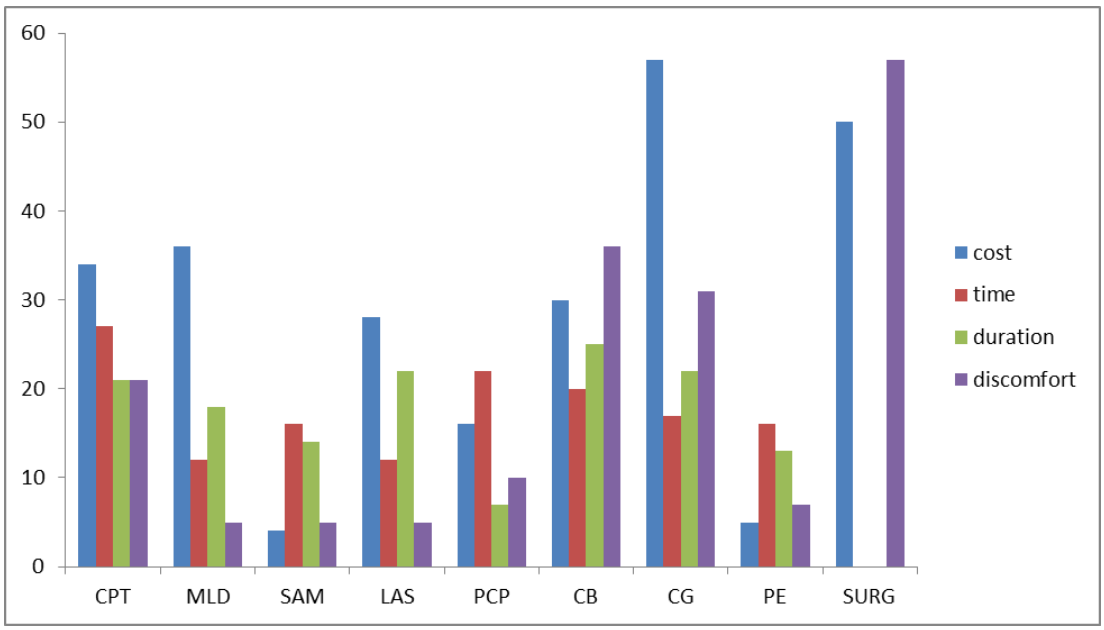

Figure 4.1 Unacceptability of the cost, time, duration and discomfort associated with treatment.

4.4.2 REASONS FOR CEASING USE OF TREATMENT

Those who stopped using treatments indicated a number a reasons for doing so (see Table 4.4). Reasons are ranked from highest to lowest for each treatment, and the reasons (excluding 'no longer needed') reported by the highest proportions of participants (across different treatments) are shaded in the table. As some participants who reported stopping the use of treatment because the treatment was 'no longer needed' had also provided other reasons for ceasing treatment use, all participants remained in the multivariable analyses.

Between 26-36% stopped using CPT, compression garments, laser therapy, and MLD (26%, 27%, 30% and 36%, respectively) because the treatment was 'too expensive'. The effort required for the continued use of prescribed exercises, compression garments and bandaging, and self-administered massage was reported as a reason for ceasing treatment by 23 to 34% of participants (23%, 23%, 25%, and 34%,

respectively). Between 23 to 40% reported self-massage, prescribed exercises, MLD and CPT as too time consuming (40%, 31%, 26%, and 23%, respectively).

At least one in four participants who stopped using prescribed exercises (26%) and self-massage (31%) did so because they felt the treatment did not improve symptoms, while 21% of participants who no longer used compression garments ceased use due to associated side effects.

Additional Reasons for ceasing treatment use

Participants' responses to open-ended questions about their reasons for stopping treatment were reviewed and grouped into themes. A number of themes coincided with the reasons listed in the questionnaire (e.g., cost, time, effort, ineffective), but additional themes included access to treatment, discomfort, inability to perform treatment, treatment being a reminder of the condition, treatment not being recommended on a long-term basis, and forgetting the treatment.

Access to treatment was a significant issue for a number of participants who had stopped using CPT and/or MLD (see Appendix G for additional examples of participants' reasons for ceasing use). Participants described barriers to accessing services (i.e., living in rural areas) and dissatisfaction with treating practitioners who they felt were not adequately trained in lymphoedema management (i.e., feeling adequate lymphoedema training was unavailable).

> *"As a country resident (150km from Melbourne) access is restricted. Local hospital physio has been trained but does not have time for CPT."* (response to Q.15h, CPT)
>
> *"I have not been able to find another physio offering this service – plenty of people who think they know – really shonky, and very worrying!"* (response to Q.16h, MLD)

Difficulties accessing treatment were also reported by participants who had stopped using laser therapy, PCP, bandaging, and compression garments.

Discomfort associated with treatment was discussed by a considerable number of participants who had stopped using compression bandaging and garments. Participants described particular difficulties in hot weather, pain, and ill-fitting garments.

> *"Found them very uncomfortable they ride down and then dig in under the knee causing pain."* (response to Q.21h, compression garments)

Reasons associated with discomfort were also described by participants who had stopped using prescribed exercises, PCP, and CPT.

Some participants who were not currently performing self-massage reported being unable to do so. Participants described not having another person who could assist them, while others felt this was too burdensome on a long-term basis.

> *"My husband did complete the 1 month as directed but found it very hard and time consuming to continue with the lymphoedema 'milking' process of my legs. It was very effective though. Trying to do it myself seemed ineffective."* (response to Q.17h, self-massage)

Being reminded of lymphoedema was also discussed as a reason for no longer using self-massage to treat symptoms. A number of participants stated they were no longer using PCP because long-term use was not recommended by their treating health professional.

> *"Told not to use outside of complex physical therapy, which I only had for 10 sessions in 1 month. Would like to have more."* (response to Q.19h, pneumatic pumps)

Table 4.4

Proportions of participants who used each treatment, who reported different reasons for ceasing use of each treatment

CPT (n=114/176)*	MLD (n=107/285)*	Self-massage (n=82/332)*	Laser (n=44/77)*	Pumps (n=44/51)*	Bandaging (n=121/188)*	Garments (n=60/362)*	Exercises (n=91/291)*
Not needed 38 (33.3)	Expensive 39 (36.4)	Time 33 (40.2)	Expensive 13 (29.5)	Not needed 10 (22.7)	Not needed 38 (31.4)	Not needed 20 (33.3)	Time 28 (30.8)
Expensive 30 (26.3)	Time 28 (26.2)	Effort 28 (34.1)	No improvement 9 (20.5)	No improvement 9 (20.5)	Time 29 (24.0)	Expensive 16 (26.7)	No improvement 24 (26.4)
Time 21 (18.4)	Not needed 27 (25.2)	No improvement 25 (30.5)	Not needed 7 (15.9)	Expensive 5 (11.4)	Effort 28 (23.1)	Effort 15 (25.0)	Effort 21 (23.1)
Effort 21 (18.4)	Effort 23 (21.5)	Not needed 23 (28.0)	Effort 4 (9.1)	Effort 3 (6.8)	No improvement 17 (14.0)	Side effects 9/43 (20.9)	Not needed 14 (15.4)
No improvement 17 (14.9)	No improvement 20 (18.7)	Expensive 8 (9.8)	Time 4 (9.1)	Time 3 (6.8)	Expensive 16 (13.2)	Time 9 (15.0)	Stopped improving 7 (7.7)
Stopped improving 15 (13.2)	Stopped improving 13 (12.1)	Stopped improving 8 (9.8)	Stopped improving 2 (4.5)	Stopped improving 1 (2.3)	Stopped improving 13 (10.7)	No improvement 9 (15.0)	Side effects 2/57 (3.5)
Side effects 4/61 (6.6)	Side effects 2/73 (2.7)	Symptoms worse 4 (4.9)	Symptoms Worse 1(2.0)	Symptoms worse 0 (0.0)	Side effects 5/71 (7.0)	Stopped improving 9 (15.0)	Symptoms worse 3 (3.3)
Symptoms worse 3 (2.6)	Symptoms worse 1 (0.9)	Side effects 3/62 (4.8)	Side effects 0 (0.0)	Side effects 0 (0.0)	Symptoms worse 5 (4.1)	Symptoms worse 8 (13.3)	Expensive 2 (2.2)

CPT: Complex physical therapy; MLD: Manual lymphatic drainage; * Number of participants who stopped using treatment/Total number who had ever used treatment

4.4.3 ASSISTANCE WITH TREATMENT

Almost half of all participants (42%) reported needing assistance from another person to complete their prescribed lymphoedema treatment. Of these, one in five did not have a support person available to assist them with treatment.

4.5 OBJECTIVE FOUR – PERCEIVED EFFECTIVENESS OF TREATMENT

Assess the perceived effectiveness of lymphoedema treatment to treat the physical symptoms of lymphoedema.

4.5.1 IMPROVEMENT IN SYMPTOMS

At least one in five, and up to 60% of participants (who experienced each symptom) perceived their lymphoedema treatment (regardless of treatment type) as effective in treating their swelling (26 to 60% across treatment types), heaviness (23 to 50%) , tightness (23 to 52%), and aching (20 to 40%) (see Table 4.5).

4.5.2 EFFECTIVENESS OF LYMPHOEDEMA TREATMENT TYPES

Proportions of patients who experienced each symptom and who found treatment effective for improving their symptoms are presented in Table 4.5 and Table 4.6. In Table 4.5, the four symptoms for which the highest proportions of participants reported improvements following treatment are shaded. The four treatments perceived as effective for improving symptoms by the highest proportions of participants are shaded in Table 4.6. At least one in two participants who used compression garments, CPT, compression bandaging, and/or surgery to treat their lymphoedema, perceived the treatment as effective in reducing swelling (60%, 60%, 52% and 50%, respectively). Half of those who used CPT also found it effective at improving heaviness (50%) and tightness (52%).

Overall, CPT, compression garments, compression bandaging and MLD were perceived as effective at improving a range of lymphoedema symptoms, by 18 to 60% of participants reporting improvements in any one symptom (see Table 4.6). Self-administered massage and prescribed exercises consistently had the lowest proportions of participants reporting the treatments as effective at improving symptoms.

Table 4.5

Proportions of participants who reported each treatment as effective for treating lymphoedema symptoms

Garments n (%)[a]	Self-massage n (%)[a]	Exercises n (%)[a]	MLD n (%)[a]	Bandaging n (%)[a]	CPT n (%)[a]	Laser therapy n (%)[a]	Pumps n (%)[a]	Surgery n (%)[a]
Swelling	Swelling	Swelling	Swelling	Swelling	Swelling	Tightness	Swelling	Swelling
216 (60.0)	86 (26.1)	78 (26.9)	132 (46.2)	98 (52.1)	105 (59.7)	34 (46.6)	22 (43.1)	7 (50.0)
Heaviness	Heaviness	RoM	Tightness	Heaviness	Tightness	Swelling	Stiffness	Heaviness
153 (46.6)	71 (23.4)	58 (24.6)	112 (42.3)	79 (46.7)	86 (51.5)	27 (35.1)	11 (32.4)	5 (38.5)
Tightness	Tightness	Tightness	Heaviness	Tightness	Heaviness	Heaviness	Tightness	Tightness
138 (42.9)	71 (23.2)	65 (24.3)	109 (41.6)	78 (44.6)	83 (50.3)	22 (30.6)	16 (32.0)	5 (35.7)
Aching	Aching	Heaviness	Aching	Aching	Aching	Aching	Heaviness	Tingling
108 (38.7)	53 (20.0)	64 (24.3)	88 (38.4)	51 (32.1)	60 (40.5)	19 (28.8)	15 (30.6)	2 (33.3)
Tenderness	Tenderness	Stiffness	Stiffness	RoM	RoM	Stiffness	RoM	RoM
74 (29.7)	34 (14.6)	43 (22.5)	53 (27.6)	44 (27.3)	53 (35.6)	13 (23.6)	14 (29.8)	4 (30.0)
Pain	Pain	Aching	Tenderness	Stiffness	Stiffness	Tenderness	Aching	Stiffness
63 (26.7)	33 (14.3)	50 (21.9)	57 (27.5)	31 (24.8)	41 (33.1)	13 (23.2)	12 (26.1)	3 (30.0)
RoM	RoM	Pain	RoM	Tenderness	Tenderness	RoM	Tenderness	Aching
69 (23.8)	38 (14.1)	33 (16.6)	61 (26.6)	32 (23.2)	41 (31.3)	14 (21.2)	8 (19.0)	3 (27.3)
Stiffness	Numbness	Tenderness	Pain	Pain	Tingling	Pain	Pain	Pain
51 (22.5)	24 (12.6)	30 (15.1)	53 (26.4)	30 (22.9)	17 (30.9)	12 (20.3)	7 (18.4)	2 (20.0)
Tingling	Stiffness	Weakness	Numbness	Tingling	Numbness	Tingling	Numbness	Tenderness
24 (20.2)	25 (11.3)	26 (14.0)	35 (21.6)	12 (21.8)	27 (25.5)	4 (19.0)	6 (18.2)	2 (20.0)
Weakness	Tingling	Numbness	Tingling	Numbness	Pain	Numbness	Weakness	Numbness
44 (19.7)	13 (10.7)	18 (11.0)	20 (19.8)	21 (19.8)	30 (23.3)	6 (13.0)	5 (14.7)	1 (14.3)
Numbness	Weakness	Tingling	Weakness	Weakness	Weakness	Weakness	Tingling	Weakness
36 (18.7)	22 (10.2)	11 (10.4)	34 (18.0)	23 (18.4)	25 (20.7)	5 (9.8)	1 (12.5)	1 (12.5)

Shading highlights the four symptoms for which the highest proportions of participants reported improvements following treatment; [a]Proportions of patients who used the treatment and had the symptom; RoM – Range of movement; MLD – manual lymphatic drainage; CPT – complex physical therapy

Table 4.6

Proportions of participants who reported improvement in lymphoedema symptoms following use of different treatments

Swelling n(%)[a]	Heaviness n(%)[a]	Tightness n(%)[a]	Aching n(%)[a]	Tenderness n(%)[a]	Stiffness n(%)[a]	Weakness n(%)[a]	Numbness n(%)[a]	Tingling n(%)[a]	Pain n(%)[a]	RoM n(%)[a]
CG	CPT	CPT	CPT	CPT	CPT	CPT	CPT	SURG	CG	CPT
216 (60.0)	83 (50.3)	86 (51.5)	60 (40.5)	41 (31.3)	41 (33.1)	25 (20.7)	27 (25.5)	2 (33.3)	63 (26.7)	53 (35.6)
CPT	CB	LAS	CG	CG	PCP	CG	MLD	CPT	MLD	SURG
105 (59.7)	79 (46.7)	34 (46.6)	108 (38.7)	74 (29.7)	11 (32.4)	44 (19.7)	35 (21.6)	17 (30.9)	53 (26.4)	4 (30.0)
CB	CG	CB	MLD	MLD	SURG	CB	CB	CB	CPT	PCP
98 (52.1)	153 (46.6)	78 (44.6)	88 (38.4)	57 (27.5)	3 (30.0)	23 (18.4)	21 (19.8)	12 (21.8)	30 (23.3)	14 (29.8)
SURG	MLD	CG	CB	CB	MLD	MLD	CG	CG	CB	CB
7 (50.0)	109 (41.6)	138 (42.9)	51 (32.1)	32 (23.2)	53 (27.6)	34 (18.0)	36 (18.7)	24 (20.2)	30 (22.9)	44 (27.3)
MLD	SURG	MLD	LAS	LAS	CB	PCP	PCP	MLD	LAS	MLD
132 (46.2)	5 (38.5)	112 (42.3)	19 (28.8)	13 (23.2)	31 (24.8)	5 (14.7)	6 (18.2)	20 (19.8)	12 (20.3)	61 (26.6)
PCP	LAS	SURG	SURG	SURG	LAS	PE	SURG	LAS	SURG	PE
22 (43.1)	22 (30.6)	5 (35.7)	3 (27.3)	2 (20.0)	13 (23.6)	26 (14.0)	1 (14.3)	4 (19.0)	2 (20.0)	58 (24.6)
LAS	PCP	PCP	PCP	PCP	CG	SURG	LAS	PCP	PCP	CG
27 (35.1)	15 (30.6)	16 (32.0)	12 (26.1)	8 (19.0)	51 (22.5)	1 (12.5)	6 (13.0)	1 (12.5)	7 (18.4)	69 (23.8)
PE	PE	PE	PE	PE	PE	SAM	SAM	SAM	PE	LAS
78 (26.9)	64 (24.3)	65 (24.3)	50 (21.9)	30 (15.1)	43 (22.5)	22 (10.2)	24 (12.6)	13 (10.7)	33 (16.6)	14 (21.2)
SAM	SAM	SAM	SAM	SAM	SAM	LAS	PE	PE	SAM	SAM
86 (26.1)	71 (23.4)	71 (23.2)	53 (20.0)	34 (14.6)	25 (11.3)	5 (9.8)	18 (11.0)	11 (10.4)	33 (14.3)	38 (14.1)

Shading highlights the four treatments for which the highest proportions of participants reported improvements in symptoms; [a]Proportions of patients who used the treatment and had the symptom; CG – Compression garments; CPT – Complex physical therapy; CB – Compression bandaging; SURG – Surgery; MLD – Manual lymphatic drainage; PCP – Pneumatic compression pumps; LAS – Laser therapy; PE – Prescribed exercises; SAM – Self-administered massage

4.6 OBJECTIVE FIVE – FACTORS INFLUENCING THE USE, ACCEPTABILITY AND EFFECTIVENESS OF LYMPHOEDEMA TREATMENT

Assess the relationships between personal characteristics, lymphoedema characteristics and the use, acceptability and perceived effectiveness of lymphoedema treatment strategies.

Bivariate relationships between factors in the conceptual model described in section 2.9 were explored one by one to examine the crude relationships between socio-demographic and condition-related factors and the use, acceptability and effectiveness of treatments. As described in section 3.12.5, bivariate results were then stratified by lymphoedema location to explore confounding and effect modification of the crude relationships. Multivariable regression modelling was then used to control for confounding. Six treatments were used by an adequate number of participants to enable these analyses. Results are presented for each of these six treatment types; compression garments (n=362), self-massage (n=332), prescribed exercises (n=291), MLD (n=285), compression bandaging (n=188), and CPT (n=176). Where the only significant differences occurred in "other" categories of an independent variable, these results were not considered meaningful, and are not further discussed.

Before conducting the multivariable analyses, independent variables were tested for collinearity, according to the rationale described in Section 3.11.3. Lymphoedema characterisation and lymphoedema duration were moderately correlated (V=0.51), but appeared to be measuring different concepts (i.e., symptoms coming and going, characterised as recurrent lymphoedema, may have only been short-term but could also be long-term), hence both variables were retained for multivariable analyses.

Relationships between income, education level and employment status were associated at the low to moderate level (all correlation coefficients were less than 0.5). These variables were entered into multivariable models in the thematic block described in Section 3.12.5, along with the other personal characteristics variables.

Effectiveness variables for 11 symptoms were moderately to highly correlated (r=0.34 to r=0.90 depending on symptoms). Effectiveness variables were entered one at a time into multivariable models of compression garment use (the treatment used

by the highest number of participants) to examine whether there were differences in the relationships between other independent variables and the outcomes, depending on symptom-specific differences. The relationships did not change, so for all further multivariable analyses, effectiveness of the treatment for reducing swelling (experienced by the highest number of participants) was used as a surrogate measure of effectiveness.

Acceptability variables (cost, time, duration and/or discomfort) were moderately correlated (τb=0.51 to τb=0.69), indicating those who found some aspect of treatment acceptable/unacceptable also found other aspects of the treatment acceptable/unacceptable. However, considering the differences between the cost, time and discomfort associated with treatment are clear, it was assumed that although these variables were related there was no overlap in the constructs these variables were measuring. On the other hand, acceptability of time and duration were correlated (τb=0.72) and it was considered that participants may have confused treatment session time and the total duration of a treatment period, so these variables were not included in the same model. As 'duration' was only added to the second questionnaire, treatment session time (included in both questionnaires and asked of all participants) was used to represent 'acceptability of time' in the multivariable models.

Bivariate Results

The crude associations between independent variables and treatment use are presented below, according to treatment type. Only those associations that remained clinically and/or statistically significant after controlling for confounding are discussed in text.

The impact of lymphoedema location on bivariate associations

All bivariate associations were stratified by lymphoedema location to identify subgroup differences. Results indicating effect modification are presented in Appendix H, and are described below. Treatment use was different across a number of independent variable categories when stratified by lymphoedema location, and varied between treatment types. Results are documented for those with full body/other lymphoedema (see Appendix H), but are not discussed in terms of effect

modification due to the very few participants in this category (<20 using any treatment type).

Compression garments

Significantly less people with ULL in the older age group (70% of participants over 75 years) were using compression garments than the younger age groups (86%, 65-74 year; 90%, 55-64 years; 84%, under 55 years). However, this was not the case for those with LLL, for whom compression garment use was similar across age groups (86-92%). The association between household income and garment use also differed between those with ULL and LLL. While a lower proportion of people with ULL in the lowest income group (77%) used garments compared with higher income groups (91%, 86%, 92%, in order of ascending income groups), there was no association between household income and garment use for those with LLL (90%, 96%, 91%, 91%, respectively).

Self-massage

The association between private health insurance and self-massage use differed between lymphoedema location subgroups. A higher proportion of those with LLL who had private health insurance (79%) used self-massage compared with those who did not have any form of private health insurance (59%), while for people with ULL the difference was clinically irrelevant (84% versus 77%).

Manual lymph drainage

Amongst those with LLL, MLD was used by a lower proportion (41%) of people in the older age group (75+years) compared with younger age groups (60-70%), while there were no clinically important differences in use across age groups (80%, 70%, 75%, 81% in order of increasing age groups) for those with ULL. The association between private health insurance and MLD use also differed between these subgroups. Within the LLL group, a higher proportion of those with private health insurance (65%) used MLD compared with those without insurance (41%), whereas similar proportions with ULL used MLD (75% versus 74%) irrespective of insurance status.

Compression bandaging

The association between age and the use of compression bandaging differed between those with ULL and LLL. A lower proportion of older participants (75+ years) with LLL (40%) used bandaging, compared with younger age groups (56% under 55 years and 60% aged 55-64 years), while there were no significant differences in the use of bandaging between age groups in the ULL group (44% under 55 years, 39% 55-64 years, 40% 65-74 years and 46% 75+ years).

Interaction terms introduced into the multivariable models based on these bivariate findings resulted in unstable models with very wide confidence intervals, due to low numbers of participants in some categories. As a result, effect modification was only examined at the bivariate level in this study.

Multivariable Results

4.6.1 USE OF COMPRESSION GARMENTS

After adjustment for a range of personal and lymphoedema characteristics, employment, income, lymphoedema characterisation (single episode/recurrent or persistent) and comorbidities were associated with compression garment use (see Table 4.7). These variables were also identified as clinically and/or statistically significant at the bivariate level.

Those with persistent lymphoedema had 2.8 times higher odds of using garments compared to those with single episode or recurrent lymphoedema (95%CI=1.21-6.37, p=0.02). Although not supported statistically, participants who were retired had lower odds of using compression garments compared to those employed full time (OR=0.48, 95%CI=0.14-1.71), while the odds were higher for those who did full time home duties (OR=2.52, 95%CI=0.41-15.42). Relative to participants with household income < $20,799, those with income of <$20,800-$36,399 had higher odds of using compression garments (OR=2.46, 95%CI= 0.72-8.44, p=0.14). The odds of using garments were higher for those suffering from 2 or more than 4 comorbid conditions (OR=3.03, 95%CI=1.10-8.35 and OR=2.52, 95%CI=0.93-6.82, respectively) compared to those with no comorbid conditions.

Table 4.7

Crude and adjusted associations between personal and lymphoedema characteristics and the use of compression garments

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Employment				0.13			0.17
Employed full time	55	1.00	ref		1.00	ref	
Part-time/casual	68	0.75	0.23-2.44		1.06	0.31-3.71	
Full time home duties	45	2.15	0.40-11.65		2.52	0.41-15.42	
Retired	209	0.45	0.17-1.20		0.48	0.14-1.71	
Other	44	0.63	0.18-2.23		0.75	0.18-3.11	
Income				0.07			0.14
<$20 799	69	1.00	ref		1.00	ref	
$20 800- $36 399	61	3.00	0.91-9.86		2.46	0.72-8.44	
$36 400 - $51 999	55	1.72	0.60-4.92		1.47	0.48-4.50	
>$52 000	86	2.05	0.79-5.35		1.25	0.40-3.93	
Did not respond	150	0.88	0.42-1.85		0.68	0.30-1.52	
Lymphoedema characterised				0.02			0.02
Single episode/recurrent	41	1.00	ref		1.00	ref	
Persistent/missing	380	2.54	1.19-5.39		2.78	1.21-6.37	
Comorbidities				0.12			0.10
None	64	1.00	ref		1.00	ref	
1 condition	104	0.99	0.44-2.26		1.14	0.48-2.72	
2 conditions	101	2.41	0.91-6.37		3.03	1.10-8.35	
3 conditions	58	0.80	0.32-1.97		1.28	0.48-3.39	
4 + conditions	94	1.74	0.69-4.39		2.52	0.93-6.82	

*All final models adjusted for age

Current use of treatment

Multivariable analyses were conducted to explore associations between current use of treatment (accepted as an indicator for continued use of treatment) and personal and lymphoedema characteristics.

Over three quarters of those who used compression garments were currently using them at the time of completing the questionnaire (79%, n=284). Current use of compression garments was not associated with any personal or demographic characteristics. However, lymphoedema location, characterisation of lymphoedema, and comorbidities, were crudely associated with current garment use (see Table 4.8). These associations remained clinically and statistically significant in the adjusted model. Those with LLL had higher odds of continued garment use (OR=2.35, 95%CI=1.32-4.19, p<0.01) compared with those with ULL. The odds of current

garment use were 2.5 times higher for those with persistent lymphoedema compared with single episode or recurrent lymphoedema (95%CI=1.10-5.59, p=<0.01). The odds of continued garment use were lower for those with 1, 2, 3 and 4 or more comorbid conditions (OR=0.25, 95%CI=0.08-0.80, OR=0.34, 95%CI=0.11-1.10, OR=0.22, 95%CI=0.06-0.76, and OR=0.18, 95%CI=0.05-0.56, respectively), when compared with those without any comorbidities (p=0.04).

Table 4.8

Crude and adjusted associations between personal and lymphoedema characteristics and current use of compression garments

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Lymphoedema location				0.01			<0.01
Upper limb	182	1.00	ref		1.00	ref	
Lower limb	163	2.31	1.33-3.99		2.35	1.32-4.19	
Full body/Other	17	0.91	0.31-2.71		0.71	0.22-2.35	
Lymphoedema characterised				<0.01			0.03
Single episode/recurrent	30	1.00	ref		1.00	ref	
Persistent/missing	332	3.14	1.45-6.79		2.48	1.10-5.59	
Comorbidities				0.06			0.04
None	53	1.00	ref		1.00	ref	
1 condition	86	0.29	0.09-0.90		0.25	0.08-0.80	
2 conditions	93	0.34	0.11-1.07		0.34	0.11-1.10	
3 conditions	46	0.21	0.06-0.69		0.22	0.06-0.76	
4 + conditions	84	0.20	0.67-0.63		0.18	0.05-0.56	

*All final models adjusted for age

Impact of acceptability and effectiveness on the current use of compression garments

The associations between perceived effectiveness, acceptability and continued use of treatment were explored using logistic regression. The personal and lymphoedema characteristics retained in the final model described above (for each treatment type) were entered into the next series of models incorporating effectiveness and acceptability variables. Separate models were run for each symptom to ensure absence of multicollinearity. For the majority of treatments and symptoms, results were consistent, and odds ratios presented and discussed in this chapter are taken from the models including the 'improved swelling' variable, to include maximum available data (i.e., swelling experienced by greatest number of participants). Final

models included adjustment for all personal or lymphoedema characteristics that were related to continued use of treatment (clinically or statistically significant).

Characterisation of lymphoedema and presence of comorbidities remained significant in the final model of current compression garment use (see Table 4.9). The acceptability of discomfort was associated with current treatment use, with those stating the discomfort when wearing garments was acceptable having higher odds of current treatment use (OR=3.13, 95% CI=1.54-6.36, p=<0.01) compared with those who reported the discomfort as unacceptable. Similarly, participants who found the time associated with garment use acceptable had 5.2 times the odds of current garment use than those who reported the time as unacceptable (95%CI=2.36-11.63, p<0.01). Those who reported that the use of compression garments improved their swelling had greater odds of reporting current garment use (OR=2.22, 95%CI=1.30-3.80).

Table 4.9

Crude and adjusted associations between personal and lymphoedema characteristics, acceptability, effectiveness and use of compression garments

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Lymphoedema location				0.01			0.11
Upper limb	182	1.00	ref		1.00	ref	
Lower limb	163	2.31	1.33-3.99		2.01	1.00-4.05	
Full body/Other	17	0.91	0.31-2.71		0.80	0.20-3.14	
Lymphoedema characterised				<0.01			<0.01
Single ep/recurrent	30	1.00	ref		1.00	ref	
Persistent/missing	332	3.14	1.45-6.79		4.31	1.62-11.46	
Comorbidities				0.06			0.10
None	53	1.00	ref		1.00	Ref	
1 condition	86	0.29	0.09-0.90		0.21	0.05-0.84	
2 conditions	93	0.34	0.11-1.07		0.36	0.09-1.42	
3 conditions	46	0.21	0.06-0.69		0.30	0.07-1.39	
4 + conditions	84	0.20	0.67-0.63		0.17	0.04-0.69	
Acceptability of Time#				<0.01			<0.01
Unacceptable	59	1.00	ref		1.00	Ref	
Neutral	74	2.00	0.93-4.32		1.77	0.78-4.00	
Acceptable	177	4.60	2.25-9.39		5.24	2.36-11.63	
Acceptability of Discomfort#				<0.01			<0.01
Unacceptable	106	1.00			1.00	ref	
Neutral	53	1.35	0.63-2.91		1.03	0.45-2.37	
Acceptable	166	3.05	1.61-5.78		3.13	1.54-6.36	
Improved swelling				<0.01			<0.01

Not effective	144	1.00	ref	1.00	Ref
Effective	216	2.36	1.42-3.92	2.22	1.30-3.80

*All final models adjusted for age
#Separate models were run for each acceptability variable. Adjusted data presented for all other variables is from the final model explaining the most variance.

4.6.2 USE OF SELF-ADMINISTERED MASSAGE

After adjustment for a range of personal and lymphoedema characteristics, age, employment, private health insurance, lymphoedema type, lymphoedema location and comorbidities were associated with use of self-administered massage (see Table 4.10). Age was inversely associated with massage use, with the odds of using massage decreasing 0.95 for each year of age (95%CI=0.92-0.98, p=<0.01). Although not statistically supported, the odds of using massage were increased for those working part-time (OR=2.25, 95%CI=0.82-6.13) or classified as full-time home duties (OR=4.59, 95%CI=1.28-16.50), when compared with participants who were employed full time (p=0.19). Participants with private health insurance had 1.8 times the odds of using massage compared with those without private (95%CI=1.00-3.14, p=0.05).

Participants with secondary lymphoedema had higher odds (OR=2.8, 95%CI=1.44-5.41) of using massage compared with primary lymphoedema (p<0.01). Similarly, participants with 4 or more comorbid conditions had greater odds of using massage compared to those with no comorbid conditions (OR=3.00, 95%CI=1.24-7.25, p=0.03). Although not statistically supported, compared to those with ULL, participants with full body/other lymphoedema had greater odds (OR=2.37, 95%CI=0.56-9.94) of using massage to treat their lymphoedema.

Table 4.10

Crude and adjusted associations between personal and lymphoedema characteristics and use of self-administered massage

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Age (continuous)	421	0.96	0.94-0.99	<0.01	0.95	0.92-0.98	<0.01
Employment				0.17			0.19
Employed full time	55	1.00	ref		1.00		
Part-time/casual	68	1.62	0.64-4.09		2.25	0.82-6.13	
Home duties	45	2.23	0.72-6.90		4.59	1.28-16.50	

Retired	209	0.82	0.40-1.67		1.91	0.74-4.94	
Other	44	1.09	0.41-2.87		1.81	0.60-5.44	
Private Health Insurance				0.01			0.05
No	96	1.00	ref		1.00	ref	
Yes	325	2.05	1.22-3.43		1.77	1.00-3.14	
Lymphoedema type				<0.01			<0.01
Primary	92	1.00	ref		1.00	ref	
Secondary	329	2.38	1.42-3.98		2.80	1.44-5.41	
Lymphoedema location				0.05			0.29
Upper limb	216	1.00	ref		1.00	ref	
Lower limb	184	0.57	0.35-0.92		0.84	0.46-1.51	
Full body/Other	21	1.24	0.35-4.43		2.37	0.56-9.94	
Comorbidities				0.14			0.03
None	64	1.00	ref		1.00	ref	
1 condition	104	1.49	0.70-3.17		1.97	0.87-4.46	
2 conditions	101	1.44	0.68-3.06		1.96	0.87-4.44	
3 conditions	58	0.68	0.31-1.50		0.90	0.38-2.12	
4 + conditions	94	1.63	0.74-3.55		3.00	1.24-7.25	

*All final models adjusted for age

Current use of treatment

Of those who used self-administered massage (SAM), 68% (n=227) were currently using massage when they participated in the study. After adjustment for all characteristics, employment was the only variable with a clinically meaningful relationship with continued use (see Table 4.11). Participants who reported their employment status as full time home duties or retired had lower odds of current massage use than those who were employed full-time (OR=0.42, 95%CI=0.15-1.17 and OR=0.49, 95%CI=0.20-1.23, respectively), but these findings were not statistically supported (p=0.43). There were no other clinically relevant or statistically significant relationships between current use of SAM and personal or lymphoedema characteristics.

Table 4.11

Crude and adjusted associations between personal and lymphoedema characteristics and current use of self-administered massage

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Employment				0.41			0.43
Employed full time	43	1.00	ref		1.00	ref	
Part-time/casual	58	0.70	0.27-1.77		0.68	0.26-1.74	
Home duties	40	0.44	0.17-1.17		0.42	0.15-1.17	

Retired	156	0.53	0.24-1.19		0.49	0.20-1.23
Other	35	0.45	0.16-1.22		0.44	0.16-1.21
*All final models adjusted for age						

Impact of acceptability and effectiveness on the use of self-administered massage

The association between employment and current use of self-administered massage remained clinically significant in the final model, for those doing full time home duties compared with those employed full time (see Table 4.12). The acceptability of the time required to conduct self-administered massage was associated with current use, with those stating the time involved in self-administering massage was acceptable or neutral having greater odds of current use compared to those who found the time involved unacceptable (OR=2.66, 95%CI=1.34-5.27 and OR=2.47, 95%CI=1.00-6.11, respectively). Participants who reported massage as effective in improving their swelling had 2.4 times the odds of current use compared to those who did not find the treatment helped (95%CI=1.15-5.10, p=0.02).

Table 4.12

Crude and adjusted associations between personal and lymphoedema characteristics, acceptability, effectiveness and use of self-administered massage

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Employment				0.41			0.49
Employed full time	43	1.00	ref		1.00	ref	
Part-time/casual	58	0.70	0.27-1.77		0.73	0.27-2.02	
Home duties	40	0.44	0.17-1.17		0.49	0.15-1.62	
Retired	156	0.53	0.24-1.19		0.61	0.22-1.69	
Other	35	0.45	0.16-1.22		0.38	0.13-1.15	
Acceptability of Time				<0.01			0.02
Unacceptable	56	1.00	ref		1.00	ref	
Neutral	46	2.13	0.91-4.95		2.47	1.00-6.11	
Acceptable	173	3.00	1.55-5.64		2.66	1.34-5.27	
Improved swelling				<0.01			0.02
Not effective	244	1.00	ref		1.00	ref	
Effective	86	3.34	1.75-6.36		2.42	1.15-5.10	
*All final models adjusted for age							

4.6.3 USE OF PRESCRIBED EXERCISES

The use of prescribed exercises was crudely associated with gender, private health insurance, education level, employment, lymphoedema type, location, duration, and diagnosing health professional. After adjustment for all personal and lymphoedema characteristics, gender, employment status and lymphoedema location had significant associations with the use of prescribed exercises (see Table 4.13). Although not statistically significant, the odds of using exercises amongst men were half those for female participants (OR=0.49, 95%CI=0.20-1.22). Those who did full-time home duties had greater odds of using exercises to treat lymphoedema than those who were employed full-time (OR=2.9, 95%CI=1.04-8.07), but again, these results were not statistically supported.

In the final model, the association between lymphoedema location and the use of prescribed exercises was statistically and clinically significant, with participants with LLL having half the odds (OR=0.51, 95%CI=0.33-0.79) of using exercises, when compared to those with ULL (p=<0.01).

Table 4.13

Crude and adjusted associations between personal and lymphoedema characteristics and use of prescribed exercises

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Gender				0.02			0.13
Female	399	1.00	ref		1.00	ref	
Male	22	0.35	0.15-0.83		0.49	0.20-1.22	
Employment				0.11			0.15
Employed full time	55	1.00	ref		1.00	ref	
Part-time/casual	68	2.01	0.92-4.38		1.89	0.84-4.28	
Home duties	45	2.86	1.12-7.30		2.90	1.04-8.07	
Retired	209	1.25	0.68-2.32		1.33	0.61-2.87	
Other	44	1.08	0.48-2.46		1.01	0.42-2.42	
Lymphoedema location				<0.01			<0.01
Upper limb	216	1.00	ref		1.00	ref	
Lower limb	184	0.47	0.31-0.72		0.51	0.33-0.79	
Full body/Other	21	1.35	0.43-4.18		1.57	0.49-4.99	

*All final models adjusted for age

Current use of treatment

In the final model adjusting for personal and lymphoedema characteristics, income and comorbidites were associated with the current use of prescribed exercises (see Table 4.14). The association between income and use of exercises was not statistically significant, but the odds of current use were higher for participants with household income over $52,000 when compared with participants with income below $20,799 (OR=2.15, 95%CI=0.91-5.10). Participants with 4 or more comorbid conditions had half the odds (OR=0.54) of those with no other medical conditions (95%CI=0.24-1.25, p=0.03).

Table 4.14

Crude and adjusted associations between personal and lymphoedema characteristics and current use of prescribed exercises

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Income				0.09			0.24
<$20 799	51	1.00	ref		1.00	ref	
$20 800- $36 399	48	1.73	0.78-3.87		1.67	0.73-3.82	
$36 400 - $51	32	1.34	0.55-3.25		1.30	0.51-3.30	
>$52 000	63	2.60	1.20-5.64		2.15	0.91-5.10	
Did not respond	97	2.32	1.16-4.67		2.19	1.06-4.52	
Comorbidities				0.01			0.03
None	42	1.00	ref		1.00	ref	
1 condition	74	1.16	0.52-2.57		1.18	0.52-2.67	
2 conditions	77	1.48	0.66-3.32		1.68	0.74-3.84	
3 conditions	33	1.28	0.48-3.39		1.50	0.54-4.13	
4 + conditions	65	0.45	0.20-0.99		0.54	0.24-1.25	

*All final models adjusted for age

Impact of acceptability and effectiveness on the use of prescribed exercises

Income remained clinically significant in the final model (see Table 4.15), after adjustment for personal and lymphoedema characteristics, acceptability variables and effectiveness. Acceptability of discomfort was associated with current use of exercises, with those reporting the discomfort as neutral or acceptable having higher odds of current use than those who found the discomfort unacceptable (OR=2.37, 95%CI=0.80-6.98 and OR=2.23, 95%CI=0.82-6.06). However, these findings were not statistically supported. Participants who found exercises effective in improving

swelling had 3 times the odds of continuing to use exercises compared with those who did not find the treatment effective (OR=3.46, 95%CI=1.67-7.21, p=<0.01).

Table 4.15

Crude and adjusted associations between personal and lymphoedema characteristics, acceptability, effectiveness and use of prescribed exercises

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Income				0.09			0.05
<$20 799	51	1.00	ref		1.00	ref	
$20 800- $36 399	48	1.73	0.78-3.87		2.15	0.85-5.46	
$36 400 - $51 999	32	1.34	0.55-3.25		1.32	0.47-3.68	
>$52 000	63	2.60	1.20-5.64		2.83	1.11-7.24	
Did not respond	97	2.32	1.16-4.67		3.36	1.42-7.95	
Acceptability of Discomfort				0.08			0.26
Unacceptable	20	1.00	ref		1.00	ref	
Neutral	64	2.69	0.96-7.51		2.37	0.80-6.98	
Acceptable	166	2.92	1.14-7.49		2.23	0.82-6.06	
Improved swelling				<0.01			<0.01
Not effective	212	1.00	ref		1.00	ref	
Effective	78	4.38	2.24-8.58		3.46	1.67-7.21	

*All final models adjusted for age

4.6.4 USE OF MANUAL LYMPHATIC DRAINAGE

At the bivariate level, the use of MLD was associated with age, private health insurance, education level, employment, income, lymphoedema type, whether lymphoedema followed cancer, lymphoedema location and duration. After adjustment for personal and lymphoedema characteristics, the associations between use of MLD and employment, lymphoedema location and comorbidities, remained significant (see Table 4.16).

Participants with LLL had lower odds of using MLD compared to those with ULL (OR=0.42, 95%CI=0.27-0.65, p<0.05). Although not statistically supported, participants who worked part-time, did home duties or were retired had lower odds of using MLD (OR=0.44, 95%CI=0.18-1.07, OR=0.40, 95%CI=0.16-0.98 and OR=0.40, 95%CI=0.16-0.98, respectively) than those who were employed full-time (p=0.37). The odds of MLD use were lower for those with 3 comorbid conditions than those with no comorbidites (OR=0.48, 95%CI=0.21-1.07), however this finding was not statistically supported (p=0.14).

Table 4.16

Crude and adjusted associations between personal and lymphoedema characteristics and use of manual lymphatic drainage

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Employment				0.20			0.37
Employed full time	55	1.00	ref		1.00	ref	
Part-time/casual	68	0.47	0.20-1.09		0.44	0.18-1.07	
Home duties	45	0.40	0.16-1.01		0.40	0.15-1.10	
Retired	209	0.41	0.19-0.85		0.40	0.16-0.98	
Other	44	0.53	0.21-1.36		0.54	0.20-1.47	
Lymphoedema location				<0.01			<0.01
Upper limb	216	1.00	ref		1.00	ref	
Lower limb	184	0.46	0.30-0.71		0.42	0.27-0.65	
Full body/Other	21	1.42	0.46-4.39		0.99	0.31-3.23	
Comorbidities				0.15			0.14
None	64	1.00	ref		1.00	ref	
1 condition	104	0.58	0.29-1.16		0.64	0.31-1.32	
2 conditions	101	0.87	0.43-1.78		0.92	0.44-1.95	
3 conditions	58	0.44	0.20-0.95		0.48	0.21-1.07	
4 + conditions	94	0.79	0.38-1.61		1.07	0.49-2.31	

*All final models adjusted for age

Current use of treatment

Over half of the participants who had ever used MLD were currently using MLD at the time of the study (58%, n=166). In the final model of current MLD use, the continued use of MLD was associated with comorbidities only. Participants with one condition (in addition to lymphoedema) had greater odds (OR=2.69, 95%CI=1.23-5.85) of current MLD use than those with no comorbid conditions. The odds of current MLD use for those with more than 2 comorbid conditions compared to those with no comorbidities were not clinically meaningful (see Table 4.17).

Table 4.17

Crude and adjusted associations between personal and lymphoedema characteristics and current use of manual lymphatic drainage

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Comorbidities				0.06			0.06
None	48	1.00	ref		1.00	ref	
1 condition	66	2.69	1.23-5.85		2.69	1.23-5.85	
2 conditions	73	1.65	0.79-3.44		1.64	0.79-3.44	

3 conditions	33	0.91	0.37-2.20		0.90	0.37-2.20
4 + conditions	66	1.39	0.66-2.93		1.38	0.65-2.93
*All final models adjusted for age						

Impact of acceptability and effectiveness on the use of manual lymphatic drainage

The current use of MLD was associated with the acceptability of the time involved in treatment sessions, and the effectiveness of MLD for improving swelling. The odds of current use of MLD were greater for those who found the treatment session time acceptable or neutral (OR=4.22, 95%CI=1.83-9.71 and OR=3.72), compared with those who did not. Participants who reported MLD as effective in improving swelling had twice the odds of current MLD use (OR=1.97, 95%CI=1.14-3.39, p=0.02) than those who found the treatment did not help their swelling (see Table 4.18).

Table 4.18

Crude and adjusted associations between personal and lymphoedema characteristics, acceptability, effectiveness and use of manual lymphatic drainage

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Comorbidities				0.06			0.06
None	48	1.00	ref		1.00	ref	
1 condition	66	2.69	1.23-5.85		2.64	1.09-6.40	
2 conditions	73	1.65	0.79-3.44		1.64	0.71-3.80	
3 conditions	33	0.91	0.37-2.20		0.73	0.27-1.97	
4 + conditions	66	1.39	0.66-2.93		1.22	0.52-2.89	
Acceptability of Time				<0.01			<0.01
Unacceptable	35	1.00	ref		1.00	ref	
Neutral	42	3.33	1.28-8.66		3.72	1.37-10.09	
Acceptable	178	4.56	2.06-10.11		4.22	1.83-9.71	
Improved swelling				<0.01			0.02
Not effective	154	1.00	ref		1.00	ref	
Effective	132	2.34	1.44-3.80		1.97	1.14-3.39	
*All final models adjusted for age							

4.6.5 USE OF COMPRESSION BANDAGING

In the final model, the use of bandaging was associated with employment and lymphoedema characterisation (see Table 4.19). The odds of using bandaging were higher for those employed full-time compared to those employed part-time (OR), and retired (=0.62, 95%CI=0.30-1.30 and OR=0.56, 95%CI=0.27-1.16, respectively,

p=0.02). Participants with persistent lymphoedema had 2.7 times the odds of using compression compared to those with single episode and recurrent lymphoedema (95%CI=1.23-5.67, p=0.01).

Table 4.19

Crude and adjusted associations between personal and lymphoedema characteristics and use of compression bandaging (crude and adjusted results)

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Age (continuous)	421	0.99	0.97-1.01	0.17	1.00	0.98-1.02	0.89
Employment				0.01			0.02
Employed full time	55	1.00	ref		1.00	ref	
Part-time/casual	68	0.55	0.27-1.13		0.62	0.30-1.30	
Home duties	45	0.87	0.40-1.92		0.91	0.39-2.14	
Retired	209	0.51	0.28-0.92		0.56	0.27-1.16	
Other	44	1.61	0.71-3.65		1.81	0.77-4.26	
Lymphoedema characterised				0.01			0.01
Single episode/recurrent	41	1.00	ref		1.00	ref	
Persistent/missing	380	2.73	1.30-5.73		2.65	1.23-5.67	
*All final models adjusted for age							

Current use of treatment

One third of participants who had used bandages were currently using the treatment at the time of completing the questionnaire (30%, n=57). The current use of bandaging was associated with gender and lymphoedema location. Men had 4.2 times the odds of current bandage use compared to females (95%CI= 1.19-14.85, p=0.02). The odds of bandage use were lower for those with full-body/other lymphoedema compared to those with ULL (OR=0.28, 95%CI=0.03-2.44). However, this finding was not statistically supported (see Table 4.20).

Table 4.20

Crude and adjusted associations between personal and lymphoedema characteristics and current use of compression bandaging

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Age (continuous)	188	1.00	0.98-1.04	0.47	1.02	0.99-1.04	0.27
Gender				0.02			0.03
Female	175	1.00	ref		1.00	ref	
Male	13	4.11	1.28-13.19		4.20	1.19-14.85	

Lymphoedema location				0.11			0.22
Upper limb	89	1.00	ref		1.00	ref	
Lower limb	89	1.69	0.89-3.21		1.44	0.73-2.82	
Full body/Other	10	0.32	0.04-2.66		0.28	0.03-2.44	
*All final models adjusted for age							

Impact of acceptability and effectiveness on the use of compression bandaging

The acceptability of the time and discomfort associated with compression bandaging were related to current use of bandaging (see Table 4.21). Participants who found the time involved with bandaging acceptable or neutral had higher odds of current bandage use than those who found the time unacceptable (OR=7.17, 95%CI=2.45-20.98 and OR=5.04, 95%CI=1.45-17.56, respectively). Similarly, participants who found the associated discomfort acceptable or neutral had significantly greater odds of current use of bandaging than those who found the discomfort unacceptable (OR=6.56, 95%CI=2.55-17.00 and OR=3.39, 95%CI=1.10-10.45, respectively). The relationship between current use of bandaging and perceived effectiveness for treating swelling was not statistically or clinically meaningful.

Table 4.21

Crude and adjusted associations between personal and lymphoedema characteristics, acceptability, effectiveness and use of compression bandaging

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Gender				0.02			0.06
Female	175	1.00	ref		1.00	ref	
Male	13	4.11	1.28-13.19		3.65	0.96-13.82	
Lymphoedema location				0.11			0.34
Upper limb	89	1.00	ref		1.00	ref	
Lower limb	89	1.69	0.89-3.21		1.16	0.53-2.57	
Full body/Other	10	0.32	0.04-2.66		0.22	0.02-2.18	
Acceptability of Time*				0.00			<0.01
Unacceptable	51	1.00	ref		1.00	ref	
Neutral	34	3.59	1.18-10.93		5.04	1.45-17.56	
Acceptable	70	5.63	2.12-14.91		7.17	2.45-20.98	
Acceptability of Discomfort				<0.01			<0.01
Unacceptable	67	1.00	ref		1.00	ref	
Neutral	30	2.76	0.97-7.89		3.39	1.10-10.45	
Acceptable	64	5.69	2.41-13.40		6.56	2.55-17.00	
*All final models adjusted for age							
**Acceptability of time from separate model							

4.6.6 USE OF COMPLEX PHYSICAL THERAPY

After adjustment for personal and lymphoedema characteristics, the use of CPT was associated with employment, income, and lymphoedema characterisation (see Table 4.22). Participants with persistent lymphoedema had 2.3 times the odds of using CPT compared with those with single episode/recurrent lymphoedema (95%CI=1.10-4.95, p=0.03). Although the odds of using CPT were lower for participants who were doing full-time home duties (OR=0.52, 95%CI=0.22-1.26) or retired (OR=0.39, 95%CI=0.18-0.86) compared to those employed full-time, and lower for participants with household income over $20,800 compared to those with household income less than $20,799 (OR=0.42, 95%CI=0.20-0.87), these findings were not statistically supported.

Table 4.22

Crude and adjusted associations between personal and lymphoedema characteristics and use of complex physical therapy

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Employment				0.22			0.22
Employed full time	55	1.00	ref		1.00	ref	
Part-time/casual	68	0.55	0.27-1.13		0.59	0.28-1.24	
Home duties	45	0.61	0.28-1.35		0.52	0.22-1.26	
Retired	209	0.51	0.28-0.92		0.39	0.18-0.86	
Other	44	0.76	0.34-1.69		0.60	0.25-1.47	
Income				0.11			0.08
<$20 799	69	1.00	ref		1.00	ref	
$20 800- $36 399	61	0.45	0.22-0.92		0.42	0.20-0.87	
$36 400 - $51 999	55	0.62	0.30-1.27		0.58	0.27-1.23	
>$52 000	86	0.75	0.40-1.42		0.55	0.26-1.18	
Did not respond	150	0.50	0.28-0.89		0.43	0.23-0.79	
Lymphoedema characterised				0.04			0.03
Single episode/recurrent	41	1.00	ref		1.00	ref	
Persistent/missing	380	2.10	1.02-4.30		2.33	1.10-4.95	

*All final models adjusted for age

Current use of treatment

Of those who had ever used CPT, 32% reported current use of CPT (n=57). The current use of CPT was associated with age, gender, employment, income, lymphoedema location and comorbidities (see Table 4.23). The odds of using CPT increased with age (OR=1.05, 95%CI=1.00-1.11, p=0.04). A number of other

variables were considered clinically important. Male participants had lower odds of current CPT use compared to females (OR=0.42, 95%CI=0.04-4.77), as did those who were employed part-time, did full-time home duties or were retired, compared to participants who were employed full-time (OR=0.45, 95%CI=0.11-1.77, OR=0.31, 95%CI=0.06-1.55 and OR=0.24, 95%CI=0.06-1.00, respectively). However, these results were not statistically significant. Participants who had a household income between $36,400 and $51,999 had higher odds than those with income less than $20 799 (OR=2.69, 95%CI=0.69-10.51), but the odds in other income groups were not clinically meaningful.

Participants with LLL and lymphoedema of the full body or other area had lower odds of current CPT use than those with ULL (OR=0.40, 95%CI=0.17-0.91 and OR=0.45, 95%CI=0.07-2.82). The odds of current CPT use were greater for those with 1, 2, 3 or more than 4 comorbid conditions (OR=4.04, 95%CI=0.89-18.42, OR=7.23, 95%CI=1.64-31.99, OR=5.09, 95%CI=0.96-26.92 and OR=5.86, 95%CI=1.23-27.79, respectively) than for those with no comorbidities. However, these associations were not statistically supported.

Table 4.23

Crude and adjusted associations between personal and lymphoedema characteristics and current use of complex physical therapy

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Age (continuous)	176	1.00	1.01-1.08	0.01	1.05	1.00-1.11	0.04
Gender				0.32			0.48
Female	169	1.00	ref		1.00	ref	
Male	7	0.34	0.04-2.86		0.42	0.04-4.77	
Employment				0.17			0.09
Employed full time	30	1.00	ref		1.00	ref	
Part-time/casual	27	1.17	0.38-3.57		0.45	0.11-1.77	
Home duties	19	1.70	0.51-5.63		0.31	0.06-1.55	
Retired	79	1.43	0.58-3.53		0.24	0.06-1.00	
Other	21	0.12	0.01-1.01		0.04	0.00-0.42	
Income				0.07			0.06
<$20 799	37	1.00	ref		1.00	ref	
$20 800- $36 399	21	1.24	0.37-4.17		1.02	0.26-3.94	
$36 400 - $51 999	23	2.00	0.65-6.16		2.69	0.69-10.51	
>$52 000	40	0.78	0.26-2.29		0.65	0.15-2.80	
Did not respond	55	2.59	1.03-6.50		2.71	0.90-8.18	
Lymphoedema location				0.06			0.08

Upper limb	95	1.00	ref		1.00	ref	
Lower limb	70	0.48	0.24-0.95		0.40	0.17-0.91	
Full body/Other	11	0.33	0.07-1.63		0.45	0.07-2.82	
Comorbidities				0.11			0.13
None	29	1.00	ref		1.00	ref	
1 condition	37	4.16	1.05-16.52		4.04	0.89-18.42	
2 conditions	45	6.33	1.67-24.03		7.23	1.64-31.99	
3 conditions	23	4.62	1.06-20.13		5.09	0.96-26.92	
4 + conditions	42	4.81	1.25-18.60		5.86	1.23-27.79	

*All final models adjusted for age

Impact of acceptability and effectiveness on the use of complex physical therapy

In the final model incorporating acceptability and effectiveness variables, gender, employment, income and comorbidities remained clinically important, and the association between lymphoedema location and current use of CPT was both statistically and clinically significant (see Table 4.24). Acceptability of discomfort and time were also found to be associated with current CPT use. Those who found the discomfort acceptable or neutral had 4 times the odds of continued use compared with those who found the associated discomfort unacceptable (OR=4.13, 95%CI=1.18-14.42 and OR=3.93, 95%CI=0.86-17.90, respectively). Similarly, participants reporting the time associated with CPT use as acceptable or neutral had higher odds of continued use (OR=3.47, 95%CI=1.07-11.20 and OR=2.18, 95%CI=0.49-9.62, respectively). Effectiveness of CPT for improving swelling was not associated with continued CPT use.

Table 4.24

Crude and adjusted associations between personal and lymphoedema characteristics, acceptability, effectiveness and use of complex physical therapy

Characteristics		Crude			Adjusted*		
	n	OR	95%CI	p	OR	95%CI	p
Age (continuous)	176	1.05	1.01-1.08	0.01	1.05	1.00-1.11	0.07
Gender				0.32			0.58
Female	169	1.00	ref		1.00	ref	
Male	7	0.34	0.04-2.86		0.47	0.03-6.74	
Employment				0.17			0.50
Employed full time	30	1.00	ref		1.00	ref	
Part-time/casual	27	1.17	0.38-3.57		0.58		
Full time home duties	19	1.70	0.51-5.63		0.31		
Retired	79	1.43	0.58-3.53		0.25		
Other	21	0.12	0.01-1.01		-		

Income				0.07			0.32
<$20 799	37	1.00	ref		1.00	ref	
$20 800- $36 399	21	1.24	0.37-4.17		0.81	0.19-3.46	
$36 400 - $51 999	23	2.00	0.65-6.16		1.42	0.32-6.18	
>$52 000	40	0.78	0.26-2.29		0.45	0.89-2.35	
Did not respond	55	2.59	1.03-6.50		1.67	0.49-5.69	
Lymphoedema location		0.06		0.04			
Upper limb	95	1.00	ref		1.00	ref	
Lower limb	70	0.48	0.24-0.95		0.34	0.14-0.81	
Full body/Other	11	0.33	0.07-1.63		0.23	0.02-2.64	
Comorbidities				0.11			0.19
None	29	1.00	ref		1.00	ref	
1 condition	37	4.16	1.05-16.52		4.92	1.00-24.18	
2 conditions	45	6.33	1.67-24.03		5.30	1.11-25.37	
3 conditions	23	4.62	1.06-20.13		2.71	0.44-16.84	
4 + conditions	42	4.81	1.25-18.60		6.54	1.25-34.22	
Acceptability of Discomfort				0.01			0.08
Unacceptable	38	1.00	ref		1.00	ref	
Neutral	28	4.03	1.09-14.84		3.93	0.86-17.90	
Acceptable	95	5.67	1.86-17.27		4.13	1.18-14.42	
Acceptability of Time**				0.03			0.11
Unacceptable	35	1.00	ref		1.00	ref	
Neutral	23	2.12	0.56-7.99		2.18	0.49-9.62	
Acceptable	99	3.74	1.34-10.47		3.47	1.07-11.20	

*All final models adjusted for age
**Acceptability of Time from separate model

4.6.7 FACTORS INFLUENCING CONTINUED USE OF TREATMENT

To summarise the associations between independent variables and continued use of treatrment across the different treatment types, clinicially and statistically significant results are presented in Table 4.25. Overall, few personal and lymphoedema characteristics were associated with continued treatment use (see Table 4.25). Patient-related factors, including acceptability of the time, cost and discomfort involved, and perceived effectiveness, were associated with continued use of all six treatments, but the specific factors most strongly associated differed for each treatment.

Table 4.25

Summary of statistically and clinically significant associations between personal characteristics, lymphoedema characteristics, acceptability and effectiveness of treatment in final models for each treatment

Variable	Compression garments	Self-administered massage	Prescribed exercises	Manual lymphatic drainage	Compression bandaging	Complex Physical therapy
Age						
Gender						
Employment						
Income						
Lymphoedema location						
Lymphoedema characterised						
Comorbidities						
Acceptability of time						
Acceptability of cost						
Acceptability of discomfort						
Improved swelling						

Light shading indicates results from final model were clinically significant (OR<0.5 or >2.0); Dark shading indicates results from final model were clinically and statistically significant ($p<0.05$)

Chapter 5: Discussion

Lymphoedema has a significant impact on affected persons' quality of life, and ongoing management is required to prevent worsening of symptoms and/or development of complications. This project makes a significant contribution to the existing lymphoedema management research by comprehensively describing treatment use, effectiveness and acceptability of treatments from the patients' perspective. While previous research has described the detrimental impact of lymphoedema, little research has investigated whether current treatment options can ease symptom burden.

Review of the literature revealed a greater research focus on BCRL, highlighting the need for consideration of the impact of lymphoedema resulting from other causes. The review undertaken as part of this research confirmed that the development of lymphoedema following gynaecological cancers has physical, psychological, social and financial impacts similar to those experienced by those with BCRL. Further, concerns specific to this subgroup were summarised from both quantitative and qualitative studies, including difficulties performing daily tasks, sitting and/or standing for long periods of time, and concerns about sexuality and intimacy.

Secondary analysis of data from a cross-sectional study investigating the patient-reported use of mainstream and CAM treatments by women with lymphoedema enabled the first description of CAM use by this population. Previous research had identified that a high proportion of people with cancer use CAM. This research found that women who developed lymphoedema following breast and gynaecological cancers also used a range of CAM treatments to manage symptoms of lymphoedema. The findings from this study highlighted the concurrent use of multiple treatments, the impact of using multiple treatments on treatment effectiveness, and possible reasons patients opt to use a range of treatments beyond mainstream therapies commonly prescribed.

A critique of reviews, evaluating the efficacy of lymphoedema treatments, was also undertaken as part of this PhD to summarise the current available evidence. In doing

so, the lack of attention given to the burden of treatment and patient-reported treatment outcomes was evident. These factors are considered important in promoting treatment adherence, which is likely to influence treatment effectiveness and thus the long-term management of lymphoedema. To further progress the research in this area, a cross-sectional study was designed and conducted, as the final component in this program of research. As part of this work, patients' perceived effectiveness of treatments for improving a wide range of symptoms was considered for the first time. The barriers to long-term use of various lymphoedema treatments, including cost, time and discomfort, were also examined in this quantitative research to examine the extent to which these factors influenced treatment use in this population. The WHO's five dimensional approach (social and economic factors, treatment-, patient- and condition-related factors, and health care system factors; described in more detail in section 2.6) to addressing long-term treatment adherence is used to discuss the way these factors relate to continued use of a range of lymphoedema treatment modalities.

This chapter discusses the treatment types and number of treatments used by people with lymphoedema, the importance of patient-reported treatment outcomes and factors influencing continued treatment use. Patient-related factors, as well as treatment-related factors (including variations in treatment prescription) are discussed in terms of how they relate to the most commonly prescribed lymphoedema treatments (compression garments, self-administered massage, prescribed exercises, MLD, bandaging and CPT). The condition-related factors and health care system factors likely to influence adherence to lymphoedema treatment are also explored. Finally, the strengths and limitations of the study are addressed, the public health significance of these findings is discussed and recommendations are made for future research directions.

5.1 LYMPHOEDEMA TREATMENT USE

Participants used a range of treatment types to manage their lymphoedema, with almost two thirds of participants in this study having used more than four treatment methods. Treatments most commonly used by participants in this study were compression garments, self-massage, prescribed exercises, and MLD. This was

consistent with the prescribing practices described by health professionals in the study by Langbecker et al. [41]. The most commonly prescribed treatments by health professionals were garments, bandages, exercises, education, massage, MLD and self-massage. Findings were also consistent with a recent study of treatment use by women with BCRL, which reported that the greatest proportions of women with lymphoedema used self-massage (89%), compression garments (80%), MLD (64%) or exercises (62%) [134]. In the current study, considering the high proportion of participants who continued to use compression garments long-term, it was likely that many were using multiple treatments concurrently. This could reflect the fact that as yet, research has been unable to determine whether treatments administered by health professionals are required on a regular basis or whether intensive periods of treatment followed by self-management are equally effective, leading to unclear treatment guidelines. It is also unclear whether one treatment is sufficient to control lymphoedema or whether a combination is always required.

Of those participants who had used a particular treatment, the majority were currently using compression garments (79%), and over half of those who used garments were currently using self-massage (68%), prescribed exercises (64%) or MLD (58%). These results suggest a high proportion of people with lymphoedema continue to use multiple treatment types to manage their symptoms. Although the proportions of participants reporting current use of CPT, bandaging or PCP appear low in comparison (32%, 30%, 12%, respectively), this reflects that these treatments are often prescribed for an intensive period rather than for long-term use. In this study, it could not be determined whether those reporting current use of CPT were continuing self-management strategies or currently having intensive professional treatment only.

The factors associated with treatment use were explored in detail and are discussed in the sections below.

5.2 TREATMENT-RELATED FACTORS ASSOCIATED WITH TREATMENT USE

Aspects of the treatment program that may influence whether patients will adhere to treatment long term include the complexity of treatment and the time involved. It is important to note that participants' descriptions of different treatments varied widely, and did not always meet the criteria for each treatment's definitions used in the

current study. The proportions of responses meeting the criteria for each treatment definition ranged from 63% for CPT, to 91% for PCP. Although treatment descriptions were provided for each treatment type within the questionnaire (see Appendix A), confusion about treatments was apparent in the written descriptions (see Appendix E). This confusion and inconsistency in treatment description may be a result of the overlapping of treatment types, with CPT including bandaging, MLD, skin care and exercises. Therefore, participants may have completed all of the above, as well as CPT, or may have used those different components but not known it as CPT. There is also evidence in the literature of complex treatment types being administered in different ways dependent on the health professional [34,41]. This can make it difficult to compare and synthesise results about treatment effectiveness, with the actual prescription of treatment varying significantly.

5.3 SOCIAL AND ECONOMIC FACTORS ASSOCIATED WITH TREATMENT USE

A number of social and economic factors have been associated with reduced adherence to treatments in other settings, including unemployment, poverty and age [77]. In the current study, there was not sufficient evidence to support the hypothesis that lymphoedema treatment use varied between participants with different social and economic profiles. There appeared to be gender differences in the odds of continued use of compression bandaging and CPT with males having higher odds of continued use of bandaging and lower odds of continued CPT use. However, with so few male participants in the current study, this would require further investigation in larger studies.

Overall, the associations between continued treatment use and patient- and condition-related factors remained, after adjustment for social and economic variables. The relevant factors identified were consistent with previous research in treatment adherence for other chronic conditions [82]. The acceptability of cost of treatment and time involved are highly relevant to whether or not people with lymphoedema will continue treatment, regardless of differences in income or employment type. Further exploration of treatment prescriptions and patients' ability to complete all aspects of a prescribed treatment program is warranted. For example, greater understanding of the resources available to patients and the burden of treatment within the contexts of

their daily life (including other competing costs, other duties outside of work commitments) could offer more insight into the role of social and economic factors in influencing lymphoedema treatment adherence.

5.4 CONDITION-RELATED FACTORS ASSOCIATED WITH TREATMENT USE

Limited research has been conducted on the relationship between characteristics of lymphoedema and treatment adherence. While some suggest lymphoedema severity, location (upper- versus lower-limb) and type (cancer related versus non-cancer related) influence adherence and treatment effectiveness [34,95,109], many aspects of these relationships remain unclear, as described in section 2.8.3 (p. 62).

Findings from the current study supported the hypothesis that lymphoedema treatment use differed between people with different lymphoedema characteristics. Frequency of symptoms and lymphoedema location were associated with continued use of some treatments, but not others. People who described their lymphoedema as persistent more often continued their use of compression garments, than those who had a single episode or described their symptoms as recurrent. This was consistent with findings from previous research exploring self-management strategies, suggesting those who had lymphoedema for longer duration were more likely to adhere to prescribed treatment [95]. However, persistence of symptoms was not associated with continued use of other treatment types.

Continued use of CPT and bandaging was much less frequent for those with lymphoedema affecting the lower-limb (CPT), full body or other area (CPT and bandaging) compared with those with ULL. It could not be determined what proportion of participants reporting continued use of CPT were referring to maintenance strategies performed at home, but participants' reasons for ceasing treatment suggested this difference was, at least in part, due to difficulties applying bandages to the lower-limbs.

Lymphoedema location was also found to be an effect modifier of the associations between age, income, private health insurance, and the use of treatment. However, due to limited power in multivariable models, these subgroup differences (between those with ULL versus LLL) were only able to be explored at the bivariate level.

Nevertheless, differences between these subgroups of lymphoedema patients warrant further investigation in larger studies.

In this study, lymphoedema severity was not measured, but previous research proposes severity of symptoms can present both as a barrier (if unable to perform treatment due to symptoms) and a motivator to treatment (reminding patients to perform regular treatment to prevent worsening of symptoms) [65,95,100,107,110]. This issue would benefit from future adherence research exploring this relationship further, incorporating objective and self-reported measures of severity.

5.5 PATIENT-RELATED FACTORS ASSOCIATED WITH TREATMENT USE

Patient satisfaction with treatment has been found to influence adherence and evidence suggests those who perceive their treatment to be effective are more likely to continue with it [112]. Associated costs, time and discomfort emerged from the literature as factors potentially influencing lymphoedema treatment adherence and effectiveness [95,97], but had not been explored in detail prior to the current study. This study found that across all treatments, a high proportion of participants reported ceasing treatment due to: financial cost, effort involved, time taken to perform treatment, and a lack of perceived improvement in symptoms. In addition, participants described accessibility, poor experiences with treating health professionals, and the discomfort associated with treatment as significant barriers to treatment adherence.

5.5.1 IMPORTANCE OF IMPROVEMENT IN LYMPHOEDEMA SYMPTOMS

The hypotheses that continued treatment use would be associated with perceived effectiveness of treatment and acceptability of treatment were supported for some treatment types. The importance of these factors is highlighted below, followed by discussion of their associations with continued treatment use for the most commonly prescribed lymphoedema treatments.

Results from the current study emphasise the need for consideration of patient-reported outcomes in studies of treatment effectiveness. Improvements in swelling, heaviness, tightness and range of movement were reported as very important treatment outcomes by 60 to 72% of participants who had each symptom. In addition,

improved function, mobility, ability to wear normal clothing, and visual appearance were considered very important by around half of the participants. These findings highlight the need to consider more than just objective measures of limb size. Findings also confirm the previous suggestion by health professionals treating people with lymphoedema, that although limb volume measurements are the most common outcome in lymphoedema treatment efficacy studies, other issues (increased function, softening of tissues, reduced shape distortion and reducing likelihood of infection) may be equally important to patients [100].

5.5.2 TREATMENT ACCEPTABLITY

Previous research suggests ongoing management is required to maintain improvements in symptoms resulting from initial lymphoedema treatment (i.e., after a period of intensive CPT) [56]. In research settings, extensive efforts may be placed on achieving optimal adherence to interventions, but in practice, long-term self-management is dependent on individuals making the decision to continue treatment [81]. This study explored the factors previously identified by health professionals and researchers as barriers to treatment (cost, time and discomfort) [95,97,100], from the patient's perspective.

The acceptability of different aspects of treatment varied between treatment types. Overall, the financial cost and discomfort associated with different modalities were the two aspects of treatment considered unacceptable by the highest proportions of participants. Half of all participants who had used compression garments and/or surgery to treat their lymphoedema reported the cost as unacceptable. Around one in three found the cost of CPT and MLD unacceptable.

Of those who had stopped using garments, CPT, MLD and laser, 26 to 36% reported doing so because the treatment was too expensive. Considering that MLD and compression garments are amongst the most commonly prescribed and used treatments [41], these findings suggest that significant numbers of patients have difficulty meeting the costs of their prescribed treatment.

Around one in three reported unacceptable levels of discomfort associated with compression bandaging and garments. Pain, intolerable tightness and other descriptions of discomfort associated with compression garment and bandage use

were given as reasons for ceasing use of treatment by a significant number of participants. This side effect of compression use has been well documented in the literature [37,103].

Half of the participants who underwent surgery found the associated discomfort unacceptable. While only a small number of participants had surgery (n=14) and between them, a range of surgical techniques was used, this is a potential cause for concern and warrants further study to explore the levels of discomfort and recovery associated with different types of surgery.

Compared with cost and discomfort, the time taken to complete treatment sessions, and the total duration of treatment periods were considered unacceptable by smaller proportions of participants overall. However, amongst those who discontinued use of treatment, the time involved was provided as the reason for stopping by up to 40% of participants (self-administered massage). It is likely the proportion of people with time concerns is lower overall, as those who have continued to use the treatments have committed the time required to perform the treatment and may consider it necessary to managing their condition.

5.5.3 TREATMENT EFFECTIVENESS

Treatment effectiveness has most often been measured by recording changes in limb volume before and after a treatment program. This enables validation of measurement methods and comparison of effect between treatment types, providing a practical outcome measure for intervention research. However, in terms of translating evidence into practice and investigating adherence to treatment, it has been noted previously that changes to symptoms may be equally as important as reductions in limb volume [100].

This was the first study to consider effectiveness of treatment for eleven different symptoms. The symptoms were considered individually as it was considered possible that a treatment which improved pain or numbness without having a significant impact on limb volume could still be considered as effective and important as a treatment which had proven effective in reducing limb size.

Overall, regardless of treatment type, participants most often experienced improvements in swelling, heaviness, tightness and aching. On the other hand, few

participants reported improvements in weakness, tingling and numbness following any treatment. Across all symptoms, the highest proportions of participants consistently reported CPT, compression garments, bandaging and MLD as the most effective for symptom improvement. There were some exceptions to this. PCP, for example, were reported as effective for improving stiffness and range of movement by higher proportions than other types of compression and MLD. Similarly, laser therapy was reported as improving tightness by close to half of the participants who used this treatment and experienced tightness. It is plausible that people use multiple treatments to improve different symptoms and that overall, optimal treatment outcomes are achieved when treatments are combined. Notably, fewer participants reported improvements in symptoms following self-massage and prescribed exercises. Further research is needed to explore whether certain types of massage and exercises improve symptoms.

Compression garments

Compression garments had been used by the majority of participants in the current study (86%). Of those, 79% were currently using compression garments at the time of the study, indicating very high adherence. Studies investigating the use of compression garments to treat ULL and LLL have found consistent reductions in limb volume, but the greatest reductions have been reported when garment use was combined with other physical therapies. In the current study, 60% of those who had used garments reported them as effective for improving swelling, and 39 to 47% reported improvements in heaviness, tightness and aching. It was unknown which treatments participants were using concurrently, precluding any conclusions about the sole contribution of compression garments to symptom improvement.

Current use of garments was higher amongst those with LLL (compared with ULL) and persistent symptoms (compared with single episode or recurrent symptoms), but was lower for those with multiple comorbid conditions (compared with no comorbidities). This could be a reflection of the impact of lower-limb symptoms on daily activities (e.g., walking, standing), motivating people to continue treatment to avoid worsening of symptoms. The lower current use amongst people with comorbidities could be due to the effort required and difficulty managing multiple

medical needs. Low adherence has been associated with comorbidities and resulting complex treatment programs for a range of chronic health problems, including diabetes, hypertension, obesity and depression [77]. Patients with multiple medical conditions may weigh up the burden of lymphoedema treatment against the severity of symptoms and impact on daily life.

Perceived effectiveness and acceptability of treatment were associated with continued use of compression garments. The odds of continued garment use were higher for those who found the time and discomfort acceptable, compared to those who found these aspects of the treatment unacceptable. Participants described the discomfort as being intolerable in hot weather, and when wearing incorrectly sized garments. In addition, the odds of current garment use were higher for those who reported the treatment as effective at improving their swelling. These findings raise a number of issues to be further investigated. For those who found garments ineffective and/or experienced significant discomfort, it would be valuable to investigate whether there were differences between the types of compression garments, frequency of fittings (to ensure the correct size), and severity of lymphoedema.

A recent study reported those with moderate and severe lymphoedema, on average, reported compression garments as "very helpful" in reducing limb size, compared to those with mild lymphoedema reporting the effect as only "helpful" [134]. However, that study described "severe" lymphoedema as swelling that "anyone would notice", which could include a wide range of limb volume differences. The same study found no association between effectiveness and garment type (off-the-shelf vs custom-made). However, these findings were limited by the small number of participants with custom-made garments (n = 28), all of whom had ULL. Also of note, the majority of women (n=82) were only using garments for "at risk" activities, as opposed to daily use. The number of participants reporting unacceptable discomfort in the current study, and the association with discontinued use, suggest a need for further research into the causes of discomfort.

For those who found the time involved in using compression garments unacceptable, it was unclear whether this referred to the time taken to apply and/or wear the garments, the time taken to attend appointments to be fitted and order garments, or some other aspect of garment use. Prescriptions of garment use vary, with some

patients only advised to wear garments for travel, others for daytime use only, and some advised to wear garments day and night. These factors could have a significant impact on the acceptability of treatment time and long-term use, and would be important to investigate in future studies. It is also an important consideration for health professionals, to be aware of individual circumstances and what may be realistic in the context of the patient's daily life (i.e., communicating that wearing garments on non-work days may still be more effective than not using the garment at all).

Self-administered massage

Self-administered massage had been used by over three quarters of participants, and almost 70% had continued use. Research into self-management of lymphoedema is minimal, compared to other treatment types, which may reflect the difficulty measuring the type and frequency of self-administered treatments, as well as adherence. Findings from the only previous study exploring the use of self-massage and skin care (in the absence of other treatments) suggested improvement in symptoms and some reductions in arm volume [135].

Around one in four participants in the current study who used self-administered massage found it effective in improving swelling, heaviness and tightness. The high adherence is quite surprising given the low proportion of participants reporting symptom improvements. The acceptability of treatment however, is high, with less than 10% considering the cost or discomfort unacceptable. As treatments were considered effective when participants indicated the treatment helped 'quite a lot' or 'very much', it is possible that using self-administered massage did induce some improvements, and the low cost and discomfort makes the treatment worthwhile to patients.

Prescribed exercises

Over two thirds of participants reported using prescribed exercises. This was a positive finding, considering treatment guidelines in the past have advised against exercise (particularly repetitive movements) due to possible risk of worsening

symptoms resulting from increased blood and lymphatic flow. However, current evidence suggests that exercise has positive effects on both physical and psychological wellbeing, and does not exacerbate the condition [2,7,44].

The description of prescribed exercises in the questionnaire referred to 'limb exercises prescribed by a health professional'. However, it was clear from the responses to the open ended question asking participants to describe their treatment, that some patients (9% LAV participants, see Table 4.2) were using whole body exercise as a lymphoedema management strategy. This information was not available for LAQ+ participants who completed the first questionnaire, so the groups were not separated. Further, while studies of exercise interventions have carefully defined exercise protocols [65,72,73,105,136,137], it is difficult to determine the impact of exercises in the context of patients' daily lives, where their adherence to what has been prescribed could vary greatly over time. The following findings related to acceptability and effectiveness should be considered in the context of these limitations.

Prescribed exercises were considered acceptable to the majority of participants, with less than 10% finding the associated cost and discomfort unacceptable. As there would be no expected costs involved with limb exercises performed by the patients themselves, it is assumed some patients were referring to either the cost of sessions with a health professional where they were taught the exercises, or the cost of sessions using whole body exercise (i.e., hydrotherapy). Of those who stopped using exercises, a third reported ceasing use due to the time involved, and around one in four felt the effort required was too great, or that they had no improvement in symptoms.

One in four reported improved range of movement following the use of prescribed exercises. Given the variation in exercises prescribed, it could not be concluded whether particular types of exercise are associated with greater perceived improvements in range of movement. This would be worth exploring in future studies, considering 85% of participants said improvement in range of movement was either important or very important to them. While findings from previous research suggest exercise does not exacerbate lymphoedema, it is acknowledged that more high quality RCTs are needed to determine whether exercise contributes to

reductions in limb volume. The consideration of a range of lymphoedema symptoms and exercise types and doses in such research would enable stronger recommendations to patients about potential benefits of using prescribed exercises.

Manual lymphatic drainage

Over two thirds of participants had used MLD. Based on participants' comments, the exact prescriptions of MLD received by patients in the current study varied markedly (see Appendix E). The technique developed by Dr. Vodder, and later adapted by Casley-Smith, involves very specific hand movements, applying light pressure, from the distal to proximal regions [57,138]. In the current study, any description of lymphatic drainage performed by a health professional was accepted as meeting the criteria for MLD. Details of the methods used by health professionals providing treatment to study participants are therefore unknown. In addition, there was considerable variation in the frequency of use, with some participants using MLD weekly, and others only every 3 months or when symptoms worsened. Nevertheless, over a third, and up to half of participants who used MLD in the current study reported improvements in swelling, tightness, heaviness and aching, and over half of the participants who had ever used MLD were currently using the treatment at the time of study participation. The time and discomfort associated with MLD were acceptable to the majority (more than 85%) of participants.

The cost of MLD was considered unacceptable by over a third of participants, and of those who were no longer using MLD, 36% reported stopping treatment because it was too expensive. These findings likely reflect the need to access private physiotherapy and/or massage therapy services. Lack of access to qualified practitioners was reported by many participants, and others specifically noted the lack of available services through the public system.

Research investigating the effect of MLD on objective measures of lymphoedema suggests it is effective when used in combination with compression therapies [52,55,59], but the evidence does not support the use of MLD as a stand-alone treatment [29,44,51,53]. In the current study, between 38 and 46% of participants with each symptom reported MLD as effective in reducing swelling, tightness, heaviness,

aching. It was unknown whether these participants were using other treatments concurrently, but considering 79% of those who had ever used compression garments were currently still using these at the time of the study, it is likely that this was the case for a significant number of participants.

Although MLD may not consistently achieve limb volume reductions, the improvement in other symptoms may be just as relevant to lymphoedema management as changes in actual limb size. Further, regular contact with a trained health professional who administers MLD could also reassure patients about the progress of their condition and assist with coping; important aspects of dealing with a chronic condition.

Compression bandaging

Compression bandaging had been used by almost half of the study participants, but only a third of those were currently using bandaging to treat their lymphoedema. Bandaging is often used as one component of CPT, and it was clear from treatment descriptions that some patients had used bandaging only in the context of an intensive period of treatment. As treatment details were not always provided, those who used bandaging alone could not be separated. It is important to consider that for those who used compression bandaging as part of a combined treatment program, it could not be determined whether aspects of treatment effectiveness and acceptability apply to bandaging alone.

A third of the participants who had used bandaging found the associated cost and discomfort unacceptable. Participants further described difficulty applying bandages, and impacts such as being unable to drive and/or continue their work when wearing bandages. Around a quarter of the participants who had stopped using compression bandaging reported doing so because of the effort involved. Some who gave reasons for stopping described being unable to apply bandages at all, while others had a partner help previously but considered the burden too great to continue long-term. In the current study, almost half of all participants (42%) reported needing assistance from another person to complete this; of these, 20% did not have a support person available who could assist them. These results confirm findings from previous

studies, suggesting difficulties applying bandages and garments can result in improper use or lower compliance [100,115]. This is an important finding and suggests a need for treating health professionals to consider individual circumstances and to be aware of the possible need for extra support, particularly for those who live alone and/or those who have difficulty applying compression bandages and/or garments.

Bandages were considered effective for improving swelling, heaviness, tightness and aching by at least a third, and up to half, of those who had used them. Previous research has found significant volume reductions following the use of compression bandages [29,44,51,53,55], but the contribution of compression alone is not well understood, as bandages are often used in combination with other treatments, as was found in the current study. Given the evidence of effectiveness of bandaging for reducing swelling and improving other symptoms, the low adherence likely reflects the unacceptability of the discomfort and cost, and feasibility of using bandages within the context of the patients' lives.

Complex physical therapy

Over a third of the participants in the current study reported using CPT. Over half of those who experienced each symptom felt CPT was effective in reducing swelling (60%), tightness (52%), heaviness (50%), and at least a third reported CPT as effective for improving aching (41%), range of movement (36%) and stiffness (33%). These positive results for around half of the participants add to the findings from the critique of reviews (see Section 2.3.15), suggesting CPT was also effective at reducing limb volume. On the other hand, a large number of participants (40 to 70% depending on the symptom) did not find CPT helpful for symptom improvement, and these results should be considered in light of the intensive nature of treatment, in terms of time, effort and cost.

Of note, almost 40% of the participants who reported using CPT described a program of treatment that did not meet the defined criteria, highlighting the vast differences in treatment prescription. Considerable variation in CPT treatment protocols was found in the previous research, with total treatment periods ranging from 5 days to 4 weeks, MLD sessions within CPT lasting 30 to 60 minutes, scheduled between daily to 3

times per week, and compression applied with the use of bandages, garments, or PCP [2,44,51,54,55,58,59]. Even more variation was seen in treatment prescriptions reported by participants in the current study, with treatment periods ranging from one week to 4 months, with MLD sessions from 20 to 60 minutes and a range of compression therapies applied. The differences in treatment prescription may reflect the burden on health professionals and services, limiting what treatment can be provided to individual patients. Some treatments are covered by private health insurance, and professionals and services may tailor a treatment program to reduce the financial burden on patients. Regardless of the reasons for different treatment protocols, the variation makes it very difficult to draw conclusions about the effectiveness and acceptability of CPT.

The research so far has been unable to identify the most effective components of CPT, and suggests ongoing therapy may be required to maintain intitial reductions achieved by intensive CPT [59]. Findings from early trials of CPT suggested the only patients who experienced a full relapse of symptoms (10%), had not complied with the maintenance phase of treatment [56]. In the current study, only 32% reported current use of CPT. While the defined prescription includes ongoing self-management through the use of compression garments, skin care and exercises, it is clear from participants' treatment descriptions that this was not always prescribed (see Appendix E). Therefore, participants reporting current use could have been receiving intensive treatment at the time of the study, or could have been completing ongoing maintenance strategies. It is plausible that the differences in perceived effectiveness found in the current study are related to different treatment protocols and adherence to ongoing maintenance.

Of all participants who used CPT, between 20-35% found either cost, time, duration or discomfort associated with treatment unacceptable. This was anticipated, given the significant commitment required of patients to complete intensive treatment programs. Around one in five people who had stopped using CPT reported doing so because the treatment was too expensive, time consuming and too much effort. Accessibility was described as a major barrier, with a significant number of patients stating the treatment was not or no longer available at all in their local area.

Lack of accessibility and inconsistency of prescription of CPT make it very difficult to draw conclusions about the acceptability and effectiveness of combined treatment programs. High proportions of participants found the combination of treatments effective for symptoms, but it is not clear whether an intensive period of the combined treatment (sometimes involving admission to a treatment centre or hospital) is any more beneficial than MLD and compression used separately. Future studies are also required to assess whether intervening early could reduce the need for intensive programs and improve outcomes.

5.6 HEALTH CARE SYSTEM FACTORS

In addition to the patient-, condition- and treatment-related factors discussed above, a number of broader issues related to the accessibility of appropriate treatment emerged from this research. Accessibility of treatment was depicted as a major barrier to treatment by many participants (see Appendix G for examples of participant responses). There were two aspects to lack of accessibility: some described being unable to physically access treatment because of location and lack of service provision in their area (particularly rural areas). Others could not access treatment because of the high demand for the services, stating they were able to access limited treatment but then were not offered any follow up treatment. Further to this, some participants had been able to access treatment but did not feel they had received appropriate advice or treatment. Many were dissatisfied with the level of knowledge about lymphoedema amongst health professionals treating their lymphoedema symptoms (see Appendix G). Similar findings have been reported previously, with limited lymphoedema knowledge being cited as a possible reason for inappropriate prescribing practices and dismissive attitudes towards patients [3,34,37]. The fact that lymphoedema management has never belonged to a specific medical speciality has been suggested as a reason for the numerous different treatment pathways patients describe [3,34].

Health professionals in Australia have previously identified the lack of support and training as a barrier to providing lymphoedema treatment [41]. A study in the UK and Canada highlighted health professionals' frustration over the lack of access to multidisciplinary care, particularly when treating patients with advanced

lymphoedema and complications [100]. It is unsurprising given these experiences of both health professionals and patients that there is confusion over treatment advice and frustration over delayed access to appropriate treatment [100,139]. Multidisciplinary centres have been established in some areas, and enable standardised diagnostic procedures, combined treatment plans based on knowledge and experience of a range of health professionals, higher continuity of treatment and improved patient satisfaction and compliance, enhancing opportunities for education training research and increased awareness of LE across disciplines [98]. Further, analysis of the cost effectiveness indicates diagnosis and adequate treatment in early stage can significantly reduce direct and indirect costs compared with treatment for advanced LE resulting from delayed or missed diagnoses [99]. The findings from the current study confirm those issues raised in previous studies, and emphasise the need for more access to information, training, and multidisciplinary care.

Another barrier related to the health care system was the cost of different treatments. Of those who had stopped using MLD, CPT, compression garments and laser therapy, at least one in four stopped using the treatment because it was too expensive. Participants described private health insurance rebates reducing, needing more compression garments than covered under health insurance policies, and having to pay for multiple garments before finding one that they were able to wear without too much discomfort. The financial burden of lymphoedema treatment has been identified in a number of previous studies [37,41,105,106], and findings from this study suggest this is a concern for many people, regardless of income or employment status.

In Australia, the level of financial support available for people with lymphoedema varies between states. The Victorian Department of Human Services funds the Lymphoedema Compression Garment Program administered by Mercy Health Lymphoedema Clinic in Melbourne, providing financial assistance to pensioners and low income earners to support their access to treatment [140]. Similarly, in Western Australia, Cancer Council WA offers a Lymphoedema Management Service, providing access to MLD, CPT and compression garment subscriptions at subsidised rates [141]. For those ineligible for these services, and certainly for those in other states

where there are no subsidised services and inadequate private health rebates, cost may present a major barrier to long-term treatment.

5.7 IMPACT OF LYMPHOEDEMA ON QUALITY OF LIFE

The majority of the research investigating the impact of lymphoedema on quality of life to date has involved women with BCRL. The review of studies investigating quality of life of women with lymphoedema following treatment for gynaecological cancers undertaken as part of this research explored the impact of lower-limb symptoms (see section 2.2.1). Findings confirmed women with LLL experienced a range of physical symptoms that impacted on their ability to perform daily activities, which is consistent with previous research conducted in the breast cancer setting. Difficulties with walking, sitting, performing self-management components, body image and sexual function were of particular concern to women with LLL following gynaecological cancer. The impact of limited mobility and restricted activities on social and work relationships was highlighted, as well as the need for clothing and footwear modifications.

In the current study, quality of life was assessed using a one-item screening scale. Participants had a median quality of life score of 5.0 (min=1.0, max=7.0, 7-point visual analogue scale). A significant proportion of participants therefore reported quality of life detriments and more work is needed to assess whether early intervention could be beneficial for these patients. Previous research has suggested quality of life is not related to limb volume [142,143], and psychological morbidity may be more closely associated with level of physical function than swelling or limb size [144]. Findings from the current study involving people with primary or secondary lymphoedema suggested improvements in function and mobility, the ability to wear normal clothing, and visual appearance, were all considered very important outcomes of lymphoedema treatment by more than half of all participants, irrespective of lymphoedema type or location. A number of participants described feeling upset, frustrated and anxious about their condition and the impact it has had on their lives, as well as their family's lives (see Appendix G).

It is evident the physical and psychological impact of lymphoedema is significant, regardless of the cause. As quality of life assessment was not a main aim of this

research. It is difficult to synthesise the current results with those of previous studies due to differences in quality of life measures used. Future, especially intervention research could benefit from using the most relevant and sensitive quality of life measures to ascertain the degree of impact.

5.8 STUDY LIMITATIONS

This research presented cross-sectional views of the variety of treatments lymphoedema patients use, continue to use, and of the factors influencing use of lymphoedema treatment. It was the first study to explore patients' perspectives of the range of treatments available for lymphoedema management. While cross-sectional studies are often used for this type of exploratory and descriptive research, a longitudinal design would enable a more thorough investigation of treatment adherence. It is possible that participants who were not using a particular treatment at the time of the study responded differently than they may have, if asked during a period of treatment use.

The difficulty with investigating treatment outcomes for a condition like lymphoedema, is that patients often use multiple treatments concurrently, making it challenging to determine which treatments are having an effect on symptoms. Incorporating patient-reported outcomes into descriptive or intervention studies where treatment protocols are carefully defined, controlled or monitored could address this issue. Further limitations of this research include generalisability of the results, possible recall bias and measurement quality, as discussed below.

5.8.1 GENERALISABILITY

Study participants were members of the LAQ, LAV, or had attended the ISL patient information session. As a result, participants may have more knowledge about their condition, or have had more access to information about different treatments, as well as support, than those with lymphoedema in the general population. These factors could lead to higher levels of treatment use in this patient subgroup and may lead to more persistent use of treatments in spite of some inconvenience. This study included participants with primary lymphoedema or secondary lymphoedema following any type of cancer, or any other trauma to the lymphatic system. This enabled representation of all lymphoedema types and is a strength of the study, considering

most intervention studies limit eligibility to secondary lymphoedema, with the majority of previous research conducted with women following breast cancer.

Estimates of lymphoedema prevalence vary significantly, and limited data is available regarding characteristics of those who develop lymphoedema. A population-based study conducted in the UK [3] enables the most appropriate comparison of patient characteristics in this Australian study (considering both are developed countries and have comparable incidence and survival rates for the most common cancers). Participants in the current study were similar in age (current study mean=66.0 years, population-based mean=66.9 years). Men were under-represented at 5% of the sample compared to 17% in the population-based study, respectively. This is likely due to recruitment being through the Lymphoedema Associations, and women typically more likely to join support groups [145]. Similar proportions of participants with both upper- (45%) and lower-limb (43%) lymphoedema were included in this study, while 41% and 58% had ULL and LLL in the population-based study, respectively. The lower proportions of men and people with LLL (compared with the population-based study) may limit the generalizability of our findings to these subgroups. There were some significant differences in the use of treatments, with only 4% using MLD and 17% using self-massage in the population-based study, compared with 67% and 79% in the current study. This may either reflect true differences in treatment use between the two countries, or reflect increased use of treatments options amongst members of a support group. This finding could suggest that patterns of treatment may have limited generalizability to people with lymphoedema in the general population. The much lower levels of treatment use in the population-based study could also suggest lymphoedema treatment availability or adherence is an even greater problem in the general population than was established in this study.

The study included participants predominantly from Queensland and Victoria, with a small number living in New South Wales. Personal characteristics did not vary significantly between states, so data were combined for all analyses. Findings may be limited in generalisability to other states and territories, and internationally, given possible differences in available treatment, health care system practices, and patient needs.

5.8.2 RECALL BIAS

Study participants may have had lymphoedema for a long period of time and were asked questions about all treatment types they had ever used to manage their symptoms. However, as participants were unlikely to have forgotten using a given treatment the impact of recall bias on the prevalence of treatments used was considered limited. It also seems unlikely that people would forget treatments which make a great difference to their symptoms. However, given the maximum age of participants of 91 years, it is possible there could be some loss of data due to memory loss. Results related to the acceptability and effectiveness could be subject to recall bias, as those who were no longer using treatment may have responded differently (i.e., considering a treatment more unacceptable or less effective because they had stopped) than they would have whilst still using the treatment. Prospective studies incorporating patient-reported measures of acceptability and treatment effect would minimise recall bias.

5.8.3 MEASUREMENT QUALITY

The study utilised a newly developed questionnaire. Personal characteristics were collected using questions used in previous research, but variables relating to lymphoedema and treatment types involved the development of new questions. Senior researchers, a physiotherapist and people with lymphoedema completed the questionnaire prior to distribution to help establish face and content validity. Participants in this process did identify that limited accessibility to treatment was missing as a potential reason for stopping treatment, and this was confirmed by a number of participants describing reasons related to accessibility in the open ended question about reasons for ceasing use. Considering the size of the questionnaire and the time taken to complete it, particularly for those who had undertaken several different treatments, it is possible some may not have responded to open-ended questions requiring a written response, even when their experience wasn't reflected completely in the closed reponses. This may have led to under-reporting of reasons for stopping, for those options not included (e.g., accessibility). Only six participants responded to the request to complete the questionnaire a second time, precluding any formal quantitative repeatability testing. However, among those six, consistency was excellent.

It is possible the title of the questionnaire “The issues faced in the treatment and management of lymphoedema” introduced reporting bias by implying people with lymphoedema inherently have problems accessing and adhering to treatment. In future work, care should be taken to ensure neutral wording of all aspects of the questionnaire.

Effectiveness for improving symptoms was measured by asking participants to rank how much a treatment had helped with each symptom, and providing categories ranging from ‘very little’ to ‘very much’. The category ‘not applicable’ was available for participants who did not have a particular symptom. These responses assumed that if a participant had a symptom, that the treatment would at least help ‘very little’, but it is possible that a participant may have felt the treatment did not help at all or made symptoms worse. This may have forced responses into an effectiveness category, where the treatment was not considered by participants to be effective. However, in this case, it is likely participants would opt for the lowest category available. As results for treatment effectiveness were based on those who indicated treatment helped ‘quite a lot’ or ‘very much’ the analysis ascertained that treatment effectiveness was not over-reported.

Treatment use questions asked participants to indicate which treatments they had used, what each treatment entailed (LAV only) and whether they were currently using each treatment. Although LAV participants were asked for how long they had been using a treatment, it is not known whether or not they had used the treatment during the whole period or had stopped and started again. In addition, participants who were not currently using a treatment may have previously used it for a significant period of time. It was considered inappropriate to use the data as an accurate reflection of treatment duration, when these details could not be clarified. Further, it was unknown whether participants were currently continuing with the treatment as prescribed, or only to some level. It is important that future research in the field considers the multiple aspects of prescribed treatments and the change of treatment use over time when measuring adherence to long-term therapies.

5.9 PUBLIC HEALTH SIGNIFICANCE OF FINDINGS

This cross-sectional study included over 400 participants from three different states of Australia, providing data on a range of treatments accessed by people with lymphoedema in different locations and health systems. The following figure summarises the findings from the current study, as they relate to the conceptual summary presented in Chapter 2 and the results presented in Chapter 4.

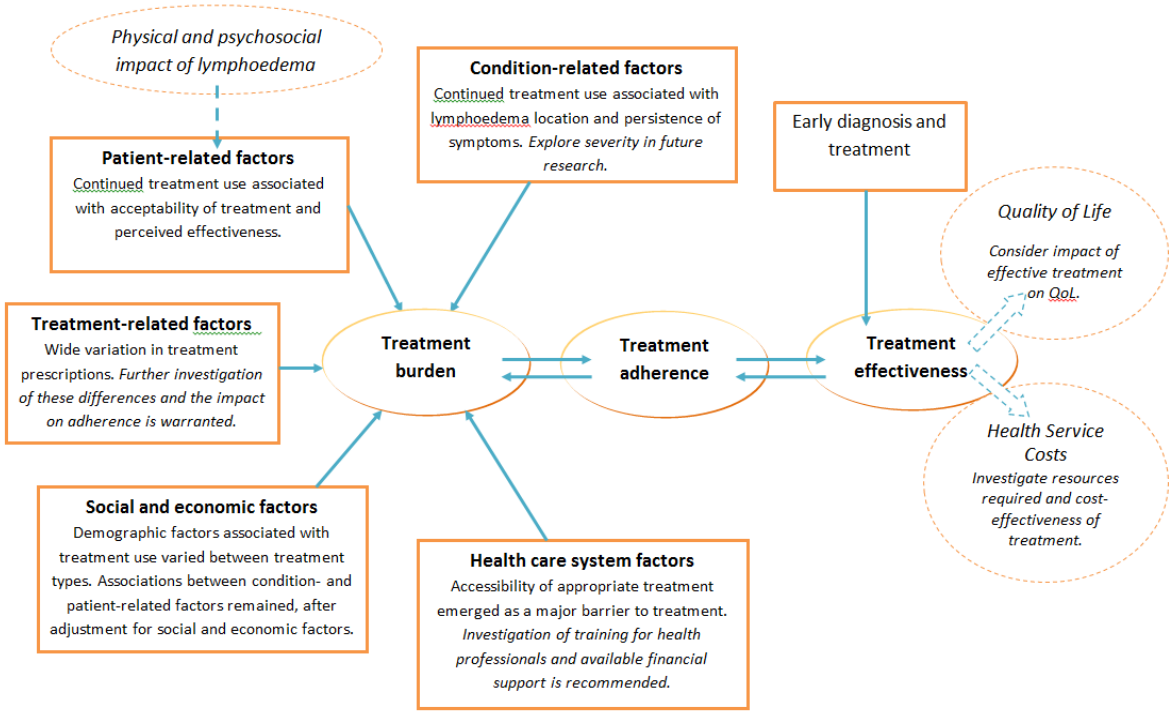

Figure 5.1 Conceptual summary with key findings from the current study and recommendations for future research

The study explored the use, acceptability and effectiveness of a range of lymphoedema treatment types, including intensive treatments, those performed by health professionals, and self-management strategies. The findings provide useful information for health professionals about the barriers faced by people undertaking long-term lymphoedema treatment, and the factors that are considered important by this patient group, relating to treatment outcomes.

Results from this study suggest that the majority of people with lymphoedema use some type of ongoing treatment to manage their condition, and many use a

combination of treatment modalities, including CAM (see section 2.4). While adherence was high for some treatments, a significant proportion of people face numerous barriers to accessing and continuing appropriate treatment. Findings from this study provide knowledge about treatment use, patients' experiences of treatment, and areas needing attention, both in future research and practice. The barriers identified here (see *Figure 2.1*) highlight that many people with lymphoedema face difficulties when trying to incorporate treatment into their daily lives on a long-term basis, as is needed to manage this chronic condition. This is also reflected in the impact lymphoedema has on quality of life (see section 2.2).

Similar patterns of treatment use have been reported interstate and internationally [134,146]. Of note, proportions of people using each treatment type in the present study were comparable to results from two other studies. Both of these also recruited participants through organisations designed to offer information and support; Breast Cancer Network Australia [134], The Lymphoedema Support Network [146]. The use of all types of treatment reported in these three studies was higher than those reported in a population-based study conducted in the UK [3]. This demonstrates the importance of such organisations for providing information and support, and highlights the significant impact this may have on patients' management of their condition. Informing patients about such supportive community organisations could be integrated into health professionals' treatment of lymphoedema, considering the chronic nature of the condition and importance of treatment adherence and self-management to maximise treatment success.

A recent Australian study of treatment use by women with BCRL suggested even amongst those with consistent lymphoedema type and location, experiences of treatment varied and no single treatment was of benefit to all women [134]. Results from a UK study relating to patients' experiences of treatments were similar to those found in the current study, with 80 to 90% reporting benefits following the use of compression garments and MLD, and less but still a high proportion (60 to 70%) reporting benefits of self-massage and exercises. It is likely these high figures reflect a single choice of 'benefit' or 'no benefit' offers to participants, compared to the more stringent criteria of 'quite a lot' or 'very much' benefit in the current study. Together with findings from the current study, these results suggest a combination of

treatment modalities may offer the greatest benefit to patients in terms of symptom improvements. Considering the impact of chronic symptoms on aspects of daily life (i.e., employment, shopping, driving, coping with chronic pain), results from this study emphasise the need for health professionals to consider improvement in individuals symptoms, and to explore the availability of alternative treatment options when patients are unable to adhere to what has been prescribed.

Access to appropriate treatment remains a significant barrier for some people with lymphoedema. Physical access to health services is likely to be a bigger issue for those in rural and remote areas, and may require careful consideration of which modalities can be most easily performed by a patient themselves, or with the help of another person (i.e., partner or other family member). A need for more awareness of lymphoedema amongst health professionals and more training in treatment provision (e.g., performing MLD) was described frequently by participants. This issue is not unique to Australia, with health professionals in the UK and Canada also acknowledging a lack of adequate training and knowledge, particularly for the management of complications associated with lymphoedema [100].

The development of multidisciplinary lymphoedema treatment centres has been shown to have widespread benefits, including improved diagnostic procedures, combined treatment plans, higher continuity of treatment and higher levels of patient satisfaction. Although considerable resources are required initially, analysis of the cost-effectiveness indicates early diagnosis and treatment can significantly reduce direct and indirect costs [99]. Participants who were able to access such services through Mercy Health Lymphoedema Clinics in Victoria for example, described positive experiences, but some were unable to access ongoing treatment, presumably due to the high demand for services, or eligibility requirements. Considering the benefits to patients and the evidence of cost-effectiveness, the development of multidisciplinary centres for the management of lymphoedema should be seen as a priority by those responsible for developing health services in other states.

5.10 FUTURE RESEARCH DIRECTIONS

Through this research, a number of factors related to lymphoedema treatment adherence were identified, which would benefit from further exploration. For

example, more thorough investigation of whether treatment needs differ for the main subgroups of lymphoedema (ULL/LLL/full body) would be beneficial. This study did not consider symptom severity, which could influence adherence in at least two ways: as a motivating reminder to continue treatment, or as a barrier to performing treatment (i.e., inability to apply compression or massage the affected area due to severe swelling). In future, where possible, it is recommended that validated tools be used to measure lymphoedema status, such as the one developed by Norman and colleagues[147]. Consistency in the measurement of lymphoedema will enable comparisons between future studies and strengthen the available evidence. Living area may influence accessibility of treatment, with available treatment options likely being limited in regional and rural areas. The impact of this on treatment adherence is worthy of further exploration.

A difficulty in exploring what really works to support treatment adherence for chronic conditions is finding the balance between measuring compliance in longitudinal intervention studies, and measuring peoples' use of treatment outside of a controlled study environment. Many aspects of intervention studies, including clearly defined treatment protocols, support through regular contact with research staff and reminders to perform treatment, are all likely to result in higher levels of adherence than may be expected outside of the research setting. Ideally, future intervention studies would include patient-reported treatment outcomes, acknowledging the importance of these factors to those being asked to use the treatment on a long-term basis. In addition, when findings from such studies suggest the given treatment is effective and treatment recommendations are made, follow up studies should explore whether such recommendations are acceptable and feasible for patients, in their less structured day to day environment.

5.11 CONCLUSION

This research has explored the impact of lymphoedema on patients' daily lives, and examined the issues faced by patients in managing lymphoedema long term. A comprehensive review of the literature confirmed that symptoms of LLL, like ULL, have a significant impact on physical function and mobility and can have widespread social and psychological implications. Managing symptoms long term often requires

a significant commitment by patients to complex treatment programs. This research examined the considerable burden of a range of commonly prescribed treatments and found that many had less than optimal effect. It was therefore not surprising that many people with lymphoedema had used a range of treatments, including various CAM treatments, in the hope of finding relief from their symptoms.

The key findings of this research provided information about the widespread symptoms suffered by many people with lymphoedema, and highlighted the need to consider these in addition to measures of limb volume in future intervention research. For many people with lymphoedema, available treatment options including compression garments and MLD were considered acceptable and effective for improving symptoms. Many reported using the treatments on a long-term basis. However, findings from this research suggested barriers such as accessibility, time commitments, symptom severity, and discomfort led to discontinued treatment, which is known to increase the risk of lymphoedema progression and complications. It is important for researchers, health care services and health professionals to consider individual circumstances and responses to treatment to maximise long-term adherence and treatment effectiveness.

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List of Appendices

APPENDIX A

Letter to participants and Questionnaire: The issues faced in the treatment and management of lymphoedema

Dear LAV members,

Researchers at the Queensland University of Technology are trying to better understand the factors which motivate and prevent people from adhering to treatment for lymphoedema. Ultimately, the information collected will be used to inform future management of lymphoedema, so that it takes into better account the key concerns for those living with lymphoedema.

The Lymphoedema Association of Victoria has kindly offered to distribute this research package to potentially eligible people on our behalf. If you choose to participate in this project, we ask that you complete the enclosed questionnaire and return it to us using the reply-paid envelope within the next 2 weeks. Your participation is voluntary, we ask for no identifying information and returning the questionnaire implies you are consenting to participate.

Following completion of the study, the results will be published in LAV's newsletter, *Swell News*. We look forward to hearing back from you and your support in our research endeavours.

Anna Finnane
Masters (Research) Student
School of Public Health
Queensland University of Technology

The issues faced in the treatment and management of lymphoedema

A Questionnaire

PARTICIPANT INFORMATION for QUT RESEARCH PROJECT

The use, acceptability and perceived effectiveness of prescribed treatments for the management of lymphoedema

Research Team Contacts	
Dr. Sandi Hayes - Senior Research Fellow *School of Public Health, Institute of Health and Biomedical Innovation, Queensland University of Technology* Phone 07 3138 9164 Email sc.hayes@qut.edu.au	Anna Finnane – PhD student *Queensland University of Technology, School of Public Health* *Victoria Park Rd, Kelvin Grove, QLD 4059* Phone 07 3138 5817 Email a.finnane@student.qut.edu.au

Description

This project is being undertaken as part of a postgraduate research project by Anna Finnane at Queensland University of Technology (QUT) under the supervision of Dr. Sandi Hayes. The purpose of this study is to develop an understanding of factors which motivate and prevent people who have, or have experienced lymphoedema, from adhering to prescribed treatments and therapies.

The research team requests your assistance because the information you provide could enable better planning and prescribing of long term treatment strategies which meet the needs of people with lymphoedema.

Participation

Your participation will involve completing a questionnaire, either in writing or by telephone. If you choose to participate, all information you provide will be anonymous. Therefore, it will not be possible to withdraw once you have submitted the questionnaire.

Expected benefits

It is expected that participation in this project will provide no immediate benefit to you. However, this project may inform future research and contribute to the planning of treatment strategies, ultimately benefiting lymphoedema patients.

Risks

The research team acknowledges that disclosing personal and health information may induce anxiety for some people. If you do not feel comfortable answering certain questions, you can skip these. An incomplete survey will still be of use to us.

QUT provides limited free counselling for research participants of QUT projects, who may experience discomfort or distress as a result of their participation in the research. Should you wish to access this service please contact the Clinic Receptionist of the QUT Psychology Clinic on 3138 0999. Please indicate to the receptionist that you are a research participant.

Confidentiality

All comments and responses are anonymous and will be treated confidentially. The names of individual persons are not required in any of the responses.

Consent to Participate

Submitting the completed questionnaire is accepted as an indication of your consent to participate in this project.

Questions / further information about the project

Please contact the researcher team members named above to have any questions answered or if you require further information about the project.

Concerns / complaints regarding the conduct of the project

QUT is committed to researcher integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Officer on 3138 2091 or ethicscontact@qut.edu.au. The Research Ethics Officer is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

The issues faced in the treatment and management of lymphoedema

Questionnaire Instructions

The questionnaire is contained in this booklet. Please try to answer all of the questions in the questionnaire that are relevant to you. If you are not sure of the correct answer, please give us your best estimate. Some questions may not directly relate to lymphoedema treatment, but will provide us with important information relating to the barriers you may face in treating your lymphoedema. If you do not feel comfortable answering certain questions, you can skip these. An incomplete questionnaire will still be of use to us.

Some of the questions have check boxes. Please read these questions carefully as some require you to tick the most correct answer, while others require you to tick all boxes that apply to you. Questions requiring a short written answer give you the opportunity to provide information you think is relevant to your experience of lymphoedema and lymphoedema treatment, which has not already been covered in the questionnaire.

Sometimes your answer to one question will allow you to skip other questions. Please read the "go to" statements carefully to ensure you are answering the questions appropriate for you. If you are uncertain about any of the questions do not hesitate to contact us:

Anna Finnane 07 3138 5817

Thank you for taking the time to complete this survey.

Before you start, please write today's date: ____/_____/____

1 Age:

_____ years

2 Are you:

Female ☐ Male ☐

3 Do you have children?

Yes ☐ ***If yes, continue below***

No ☐ ***If no, go to question 4***

How many children are younger than 5 years? ☐

How many children are aged between 5 and 14 years? ☐

How many children are older than 14 years? ☐

How many children, of any age, are living in your care? ☐

4 Currently, what is your **main** work arrangement? *(please tick one box)*

Employed/Self-employed – full-time ☐

Employed/Self-employed – part-time ☐

Employed/Self-employed – casual ☐

Full-time home duties ☐

Student ☐

Unemployed or looking for work ☐

Retired ☐

Permanently ill/unable to work ☐

Unpaid work in a family business or farm ☐

Unpaid voluntary worker ☐

Other (*please specify*) _____ ☐

5 What side do you consider your dominant side (usually the hand that you write with)?

Right ☐ Left ☐ Both ☐

6 Have you ever been diagnosed with lymphoedema (swelling) in the arm, breast, trunk, groin area or legs?

Yes ☐ No ☐

7 If you have been diagnosed with lymphoedema, please complete the following table:

	Where? (mark with an 'x' all that apply)	Date of diagnosis (approx. month and year)	Who diagnosed you? (physiotherapist surgeon, GP, massage therapist, self, other)	Did your lymphoedema last for 3 months or longer? (yes/no)	How would you characterise your lymphoedema? Single episode, Recurrent (comes and goes) or Persistent (almost always there)
right arm					
right hand					
right breast					
right trunk					
right leg					
right foot					
left arm					
left hand					
left breast					
left trunk					
left leg					
left foot					
groin area					
other					

8 Do you currently have lymphoedema?

Yes ☐ No ☐

9 Was the lymphoedema you were diagnosed with considered primary (inherited) or secondary (following cancer or injury to the lymphatic system)?

Primary ☐ **If primary, go to Question 11**

Secondary ☐

10 Did your lymphoedema occur following treatment for cancer?

Yes ☐

No ☐ Did your lymphoedema follow Injury ☐

Other ☐ _____

11 Have you ever been diagnosed with cancer?

Yes	☐	**If yes, please indicate which cancer (tick all that apply):**	
Breast	☐	Cervix	☐
Prostate	☐	Vulva	☐
Uterus	☐	Bladder	☐
Ovary	☐	Melanoma	☐
Other (*please specify*)	☐	_____	
No	☐	**If no, go to Question 14**	

12 When were you first diagnosed with cancer?

____ /____ / ____

13 What treatment have you had for your cancer?

	Yes	No	Don't know	When (mm/yyyy)?
Surgery	☐	☐	☐	_____
Chemotherapy	☐	☐	☐	_____
Radiation therapy	☐	☐	☐	_____
Hormone therapy	☐	☐	☐	_____
Other (*please specify*) _____	☐	☐	☐	_____

14 Have you had any of the following conditions? If yes, please state the approximate date you were first diagnosed with this condition.

	Yes	No	Don't know	Date of diagnosis
Heart attack (coronary, myocardial infarction)	☐	☐	☐	_____
Angina pectoris	☐	☐	☐	_____
High blood pressure	☐	☐	☐	_____
High cholesterol	☐	☐	☐	_____
Other heart condition (specify):_____	☐	☐	☐	_____
Stroke	☐	☐	☐	_____
Diabetes	☐	☐	☐	_____
Asthma	☐	☐	☐	_____
Chronic Bronchitis	☐	☐	☐	_____
Emphysema of the lungs	☐	☐	☐	_____
Stomach or duodenal ulcer	☐	☐	☐	_____
Migraine headaches	☐	☐	☐	_____
Osteoporosis	☐	☐	☐	_____
Rheumatoid arthritis	☐	☐	☐	_____
Depression	☐	☐	☐	_____
Any other prolonged serious illness – if yes, please specify: _____	☐	☐	☐	_____

The questions on the following 10 pages relate specifically to treatments you may have used to treat your lymphoedema. Each page has a series of questions about a specific treatment, which appear on both sides of the page. Please answer the yes/no question at the beginning of each page, and continue with the following questions only if you have used that treatment.

To help you determine which treatment strategies you have used, brief descriptions are provided below. If you tick a box, then you know to proceed to the coloured page that is listed.

Complex physical therapy ☐ **Questions 15 a-h**
Involves 2-4 weeks of manual lymph drainage (described below), followed by compression bandaging, skin care and prescribed limb exercises undertaken by the patient. If you have used these in **combination,** please tick here; if you only use one or two of the treatments mentioned, then do not tick here, but rather tick below for each single treatment.

Manual lymphatic drainage ☐ **Questions 16 a-h**
Administered by a health professional, manual lymphatic drainage uses various light massage techniques moving up and down the limb.

Self massage ☐ **Questions 17 a-h**
Involves a simplified version of manual lymph drainage using 'sweeping' strokes applied by you or someone else.

Laser therapy ☐ **Questions 18 a-h**
Uses a device that emits low-intensity wavelengths, also known as a scanning or spot laser.

Pneumatic pumps ☐ **Questions 19 a-h**
Uses pumps (with single or multiple chambers) that surround the limb, inflating and deflating at different cycles and pressures.

Compression bandaging ☐ **Questions 20 a-h**
Consists of a gauze sleeve, soft cotton wrap or high-density foam and two or three layers of short-stretch bandaging.

Compression garment ☐ **Questions 21 a-h**
Provides greatest compression at the furthest end of the limb and least at the end closest to the trunk.

Prescribed exercises ☐ **Questions 22 a-h**
Limb exercises prescribed by a health professional to reduce excess fluid and improve range of movement.

Surgery ☐ **Questions 23 a-h**
Any surgical procedure used to treat lymphoedema.

Other ☐ **Questions 24 a-h**
Any other treatment method used to treat your lymphoedema.

15a Have you used **complex physical therapy** to treat your lymphoedema?

Yes ☐ No ☐ **Please go to Question 16**

b Who prescribed this treatment?

Physiotherapist ☐ Massage Therapist ☐ GP ☐

Self ☐ Other (please specify) ☐ _____

c In your own words, please tell us what this treatment entails (i.e., tell us what was prescribed, how often you attended sessions, how long each session was and the length of the total prescribed treatment period):

_____

_____

_____

d Were you able to complete this treatment as prescribed?

Yes, always ☐ Yes, sometimes ☐ Rarely ☐ Never ☐

e Are you currently using this treatment?

Yes ☐ No ☐

f How acceptable do/did you find the following aspects of **complex physical therapy** as a treatment for lymphoedema?

Financial Cost:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Time required per session/day:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Duration of total prescribed treatment period (months/years/ongoing):

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Level of discomfort during treatment:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptabl	Neutral	Somewhat acceptable	Very acceptable

g Did **complex physical therapy** help with the following symptoms of lymphoedema? If you do not experience any of the symptoms, mark the "not applicable" box.

	Very little/ Little	Somewhat/ Moderately	Quite a lot/ Very much	
Swelling	☐	☐	☐	Not applicable ☐
Heaviness	☐	☐	☐	Not applicable ☐
Tightness	☐	☐	☐	Not applicable ☐
Aching	☐	☐	☐	Not applicable ☐
Tenderness	☐	☐	☐	Not applicable ☐
Stiffness	☐	☐	☐	Not applicable ☐
Weakness	☐	☐	☐	Not applicable ☐
Numbness	☐	☐	☐	Not applicable ☐
Tingling (pins & needles)	☐	☐	☐	Not applicable ☐
Pain	☐	☐	☐	Not applicable ☐
Range of movement	☐	☐	☐	Not applicable ☐

h If you are not currently using **complex physical therapy**, please indicate why not by ranking all that apply (eg. number 1 to 7) where 1 = the main reason:

No longer needed (treatment was effective) ☐	Did not improve symptoms ☐
Too expensive ☐	Stopped improving symptoms ☐
Too much effort ☐	Made symptoms worse ☐
Too time consuming ☐	Stopped due to side effects ☐

If there was another reason you are not currently using **complex physical therapy**, please tell us here:

_____

_____

_____

_____

16a Have you used **manual lymphatic drainage** to treat your lymphoedema?

Yes ☐ No ☐ **Please go to Question 17**

b Who prescribed this treatment?

Physiotherapist ☐ Massage Therapist ☐ GP ☐

Self ☐ Other (please specify) ☐ _____

c In your own words, please tell us what this treatment entails (i.e., tell us what was prescribed, how often you attended sessions, how long each session was and the length of the total prescribed treatment period):

_____

_____

_____

d Were you able to complete this treatment as prescribed?

Yes, always ☐ Yes, sometimes ☐ Rarely ☐ Never ☐

e Are you currently using this treatment?

Yes ☐ No ☐

f How acceptable do/did you find the following aspects of **manual lymphatic drainage** as a treatment for lymphoedema?

Financial Cost:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Time required per session/day:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Duration of total prescribed treatment period (months/years/ongoing):

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Level of discomfort during treatment:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

g Did **manual lymphatic drainage** help with the following symptoms of lymphoedema? If you do not experience any of the symptoms, mark the "not applicable" box.

	Very little/ Little	Somewhat/ Moderately	Quite a lot/ Very much	
Swelling	☐	☐	☐	Not applicable ☐
Heaviness	☐	☐	☐	Not applicable ☐
Tightness	☐	☐	☐	Not applicable ☐
Aching	☐	☐	☐	Not applicable ☐
Tenderness	☐	☐	☐	Not applicable ☐
Stiffness	☐	☐	☐	Not applicable ☐
Weakness	☐	☐	☐	Not applicable ☐
Numbness	☐	☐	☐	Not applicable ☐
Tingling (pins & needles)	☐	☐	☐	Not applicable ☐
Pain	☐	☐	☐	Not applicable ☐
Range of movement	☐	☐	☐	Not applicable ☐

h If you are not currently using **manual lymphatic drainage**, please indicate why not by ranking all that apply (eg. number 1 to 7) where 1 = the main reason:

No longer needed (treatment was effective)	☐	Did not improve symptoms	☐
Too expensive	☐	Stopped improving symptoms	☐
Too much effort	☐	Made symptoms worse	☐
Too time consuming	☐	Stopped due to side effects	☐

If there was another reason you are not currently using **manual lymphatic drainage**, please tell us here:

_____

_____

_____

_____

17a Have you used **self massage** (applied by you or someone else) to treat your lymphoedema?

Yes ☐ No ☐ **Please go to Question 18**

b Who prescribed this treatment?

Physiotherapist ☐ Massage Therapist ☐ GP ☐

Self ☐ Other (please specify) ☐ _____

c In your own words, please tell us what this treatment entails (i.e., tell us what was prescribed, how often you attended sessions, how long each session was and the length of the total prescribed treatment period):

_____

_____

_____

d Were you able to complete this treatment as prescribed?

Yes, always ☐ Yes, sometimes ☐ Rarely ☐ Never ☐

e Are you currently using this treatment?

Yes ☐ No ☐

f How acceptable do/did you find the following aspects of **self massage** as a treatment for lymphoedema?

Financial Cost:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Time required per session/day:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Duration of total prescribed treatment period (months/years/ongoing):

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Level of discomfort during treatment:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

g Did **self massage** help with the following symptoms of lymphoedema? If you do not experience any of the symptoms, mark the "not applicable" box.

	Very little/ Little	Somewhat/ Moderately	Quite a lot/ Very much	
Swelling	☐	☐	☐	Not applicable ☐
Heaviness	☐	☐	☐	Not applicable ☐
Tightness	☐	☐	☐	Not applicable ☐
Aching	☐	☐	☐	Not applicable ☐
Tenderness	☐	☐	☐	Not applicable ☐
Stiffness	☐	☐	☐	Not applicable ☐
Weakness	☐	☐	☐	Not applicable ☐
Numbness	☐	☐	☐	Not applicable ☐
Tingling (pins & needles)	☐	☐	☐	Not applicable ☐
Pain	☐	☐	☐	Not applicable ☐
Range of movement	☐	☐	☐	Not applicable ☐

h If you are not currently using **self massage**, please indicate why not by ranking all that apply (eg. number 1 to 7) where 1 = the main reason:

No longer needed (treatment was effective)	☐	Did not improve symptoms	☐
Too expensive	☐	Stopped improving symptoms	☐
Too much effort	☐	Made symptoms worse	☐
Too time consuming	☐	Stopped due to side effects	☐

If there was another reason you are not currently using **self massage**, please tell us here:

_____

_____

_____

_____

18a Have you used **laser therapy** to treat your lymphoedema?

Yes ☐ No ☐ **Please go to Question 19**

b Who prescribed this treatment?

Physiotherapist ☐ Massage Therapist ☐ GP ☐

Self ☐ Other (please specify) ☐ _____

c In your own words, please tell us what this treatment entails (i.e., tell us what was prescribed, how often you attended sessions, how long each session was and the length of the total prescribed treatment period):

_____

_____

_____

d Were you able to complete this treatment as prescribed?

Yes, always ☐ Yes, sometimes ☐ Rarely ☐ Never ☐

e Are you currently using this treatment?

Yes ☐ No ☐

f How acceptable do/did you find the following aspects of **laser therapy** as a treatment for lymphoedema?

Financial Cost:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Time required per session/day:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Duration of total prescribed treatment period (months/years/ongoing):

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Level of discomfort during treatment:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

g Did **laser therapy** help with the following symptoms of lymphoedema? If you do not experience any of the symptoms, mark the "not applicable" box.

	Very little/ Little	Somewhat/ Moderately	Quite a lot/ Very much	
Swelling	☐	☐	☐	Not applicable ☐
Heaviness	☐	☐	☐	Not applicable ☐
Tightness	☐	☐	☐	Not applicable ☐
Aching	☐	☐	☐	Not applicable ☐
Tenderness	☐	☐	☐	Not applicable ☐
Stiffness	☐	☐	☐	Not applicable ☐
Weakness	☐	☐	☐	Not applicable ☐
Numbness	☐	☐	☐	Not applicable ☐
Tingling (pins & needles)	☐	☐	☐	Not applicable ☐
Pain	☐	☐	☐	Not applicable ☐
Range of movement	☐	☐	☐	Not applicable ☐

h If you are not currently using **laser therapy**, please indicate why not by ranking all that apply (eg. number 1 to 7) where 1 = the main reason:

No longer needed (treatment was effective) ☐	Did not improve symptoms ☐
Too expensive ☐	Stopped improving symptoms ☐
Too much effort ☐	Made symptoms worse ☐
Too time consuming ☐	Stopped due to side effects ☐

If there was another reason you are not currently using **laser therapy**, please tell us here:

_____

_____

_____

_____

19a Have you used **pneumatic pumps** to treat your lymphoedema?

Yes ☐ No ☐ **Please go to Question 20**

b Who prescribed this treatment?

Physiotherapist ☐ Massage Therapist ☐ GP ☐

Self ☐ Other (please specify) ☐ _____

c In your own words, please tell us what this treatment entails (i.e., tell us what was prescribed, how often you attended sessions, how long each session was and the length of the total prescribed treatment period):

_____

_____

_____

d Were you able to complete this treatment as prescribed?

Yes, always ☐ Yes, sometimes ☐ Rarely ☐ Never ☐

e Are you currently using this treatment?

Yes ☐ No ☐

f How acceptable do/did you find the following aspects of **pneumatic pumps** as a treatment for lymphoedema?

Financial Cost:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Time required per session/day:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Duration of total prescribed treatment period (months/years/ongoing):

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Level of discomfort during treatment:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

g Did **pneumatic pumps** help with the following symptoms of lymphoedema? If you do not experience any of the symptoms, mark the "not applicable" box.

	Very little/ Little	Somewhat/ Moderately	Quite a lot/ Very much	
Swelling	☐	☐	☐	Not applicable ☐
Heaviness	☐	☐	☐	Not applicable ☐
Tightness	☐	☐	☐	Not applicable ☐
Aching	☐	☐	☐	Not applicable ☐
Tenderness	☐	☐	☐	Not applicable ☐
Stiffness	☐	☐	☐	Not applicable ☐
Weakness	☐	☐	☐	Not applicable ☐
Numbness	☐	☐	☐	Not applicable ☐
Tingling (pins & needles)	☐	☐	☐	Not applicable ☐
Pain	☐	☐	☐	Not applicable ☐
Range of movement	☐	☐	☐	Not applicable ☐

h If you are not currently using **pneumatic pumps**, please indicate why not by ranking all that apply (eg. number 1 to 7) where 1 = the main reason:

No longer needed (treatment was effective)	☐	Did not improve symptoms	☐
Too expensive	☐	Stopped improving symptoms	☐
Too much effort	☐	Made symptoms worse	☐
Too time consuming	☐	Stopped due to side effects	☐

If there was another reason you are not currently using **pneumatic pumps**, please tell us here:

_____

_____

_____

_____

20a Have you used **compression bandaging** to treat your lymphoedema?

Yes ☐ No ☐ **Please go to Question 21**

b Who prescribed this treatment?

Physiotherapist ☐ Massage Therapist ☐ GP ☐

Self ☐ Other (please specify) ☐ _____

c In your own words, please tell us what this treatment entails (i.e., tell us what was prescribed, how often you attended sessions, how long each session was and the length of the total prescribed treatment period):

_____

_____

_____

d Were you able to complete this treatment as prescribed?

Yes, always ☐ Yes, sometimes ☐ Rarely ☐ Never ☐

e Are you currently using this treatment?

Yes ☐ No ☐

f How acceptable do/did you find the following aspects of **compression bandaging** as a treatment for lymphoedema?

Financial Cost:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Time required per session/day:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Duration of total prescribed treatment period (months/years/ongoing):

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Level of discomfort during treatment:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

g Did **compression bandaging** help with the following symptoms of lymphoedema? If you do not experience any of the symptoms, mark the "not applicable" box.

	Very little/ Little	Somewhat/ Moderately	Quite a lot/ Very much	
Swelling	☐	☐	☐	Not applicable ☐
Heaviness	☐	☐	☐	Not applicable ☐
Tightness	☐	☐	☐	Not applicable ☐
Aching	☐	☐	☐	Not applicable ☐
Tenderness	☐	☐	☐	Not applicable ☐
Stiffness	☐	☐	☐	Not applicable ☐
Weakness	☐	☐	☐	Not applicable ☐
Numbness	☐	☐	☐	Not applicable ☐
Tingling (pins & needles)	☐	☐	☐	Not applicable ☐
Pain	☐	☐	☐	Not applicable ☐
Range of movement	☐	☐	☐	Not applicable ☐

h If you are not currently using **compression bandaging**, please indicate why not by ranking all that apply (eg. number 1 to 7) where 1 = the main reason:

No longer needed (treatment was effective)	☐	Did not improve symptoms	☐
Too expensive	☐	Stopped improving symptoms	☐
Too much effort	☐	Made symptoms worse	☐
Too time consuming	☐	Stopped due to side effects	☐

If there was another reason you are not currently using **compression bandaging**, please tell us here:

_____

_____

_____

_____

21a Have you used **compression garments** to treat your lymphoedema?

Yes ☐ No ☐ **Please go to Question 22**

b Who prescribed this treatment?

Physiotherapist ☐ Massage Therapist ☐ GP ☐

Self ☐ Other (please specify) ☐ _____

c In your own words, please tell us what this treatment entails (i.e., tell us what was prescribed, how often you attended sessions, how long each session was and the length of the total prescribed treatment period):

_____

_____

_____

d Were you able to complete this treatment as prescribed?

Yes, always ☐ Yes, sometimes ☐ Rarely ☐ Never ☐

e Are you currently using this treatment?

Yes ☐ No ☐

f How acceptable do/did you find the following aspects of **compression garments** as a treatment for lymphoedema?

Financial Cost:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Time required per session/day:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Duration of total prescribed treatment period (months/years/ongoing):

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Level of discomfort during treatment:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

g Did **compression garments** help with the following symptoms of lymphoedema? If you do not experience any of the symptoms, mark the "not applicable" box.

	Very little/ Little	Somewhat/ Moderately	Quite a lot/ Very much	
Swelling	☐	☐	☐	Not applicable ☐
Heaviness	☐	☐	☐	Not applicable ☐
Tightness	☐	☐	☐	Not applicable ☐
Aching	☐	☐	☐	Not applicable ☐
Tenderness	☐	☐	☐	Not applicable ☐
Stiffness	☐	☐	☐	Not applicable ☐
Weakness	☐	☐	☐	Not applicable ☐
Numbness	☐	☐	☐	Not applicable ☐
Tingling (pins & needles)	☐	☐	☐	Not applicable ☐
Pain	☐	☐	☐	Not applicable ☐
Range of movement	☐	☐	☐	Not applicable ☐

h If you are not currently using **compression garments**, please indicate why not by ranking all that apply (eg. number 1 to 7) where 1 = the main reason:

No longer needed (treatment was effective)	☐	Did not improve symptoms	☐
Too expensive	☐	Stopped improving symptoms	☐
Too much effort	☐	Made symptoms worse	☐
Too time consuming	☐	Stopped due to side effects	☐

If there was another reason you are not currently using **compression garments**, please tell us here:

_____

_____

_____

_____

22a Have you used **prescribed exercises** to treat your lymphoedema?

Yes ☐ No ☐ **Please go to Question 23**

b Who prescribed this treatment?

Physiotherapist ☐ Massage Therapist ☐ GP ☐

Self ☐ Other (please specify) ☐ _____

c In your own words, please tell us what this treatment entails (i.e., tell us what was prescribed, how often you attended sessions, how long each session was and the length of the total prescribed treatment period):

_____

_____

_____

d Were you able to complete this treatment as prescribed?

Yes, always ☐ Yes, sometimes ☐ Rarely ☐ Never ☐

e Are you currently using this treatment?

Yes ☐ No ☐

f How acceptable do/did you find the following aspects of **prescribed exercises** as a treatment for lymphoedema?

Financial Cost:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Time required per session/day:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Duration of total prescribed treatment period (months/years/ongoing):

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Level of discomfort during treatment:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

g Did **prescribed exercises** help with the following symptoms of lymphoedema? If you do not experience any of the symptoms, mark the "not applicable" box.

	Very little/ Little	Somewhat/ Moderately	Quite a lot/ Very much	
Swelling	☐	☐	☐	Not applicable ☐
Heaviness	☐	☐	☐	Not applicable ☐
Tightness	☐	☐	☐	Not applicable ☐
Aching	☐	☐	☐	Not applicable ☐
Tenderness	☐	☐	☐	Not applicable ☐
Stiffness	☐	☐	☐	Not applicable ☐
Weakness	☐	☐	☐	Not applicable ☐
Numbness	☐	☐	☐	Not applicable ☐
Tingling (pins & needles)	☐	☐	☐	Not applicable ☐
Pain	☐	☐	☐	Not applicable ☐
Range of movement	☐	☐	☐	Not applicable ☐

h If you are not currently using **prescribed exercises**, please indicate why not by ranking all that apply (eg. number 1 to 7) where 1 = the main reason:

No longer needed (treatment was effective)	☐	Did not improve symptoms	☐
Too expensive	☐	Stopped improving symptoms	☐
Too much effort	☐	Made symptoms worse	☐
Too time consuming	☐	Stopped due to side effects	☐

If there was another reason you are not currently using **prescribed exercises**, please tell us here:

_____

_____

_____

_____

23a Have you had **surgery** to treat your lymphoedema?

Yes ☐ No ☐ **Please go to Question 24**

b In your own words, please tell us what this treatment entailed (i.e., tell us what was prescribed and whether this involved one surgical procedure or more):

_____

_____

_____

c Were you able to complete this treatment as prescribed?

Yes, always ☐ Yes, sometimes ☐ Rarely ☐ Never ☐

d Have you already completed this treatment?

Yes ☐ No ☐

e Do you expect to have more surgery to treat your lymphoedema?

Yes ☐ No ☐

f How acceptable do/did you find the following aspects of **surgery** as a treatment for lymphoedema?

Financial Cost:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Length of treatment and recovery period:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Level of discomfort during recovery:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

g Did **surgery** help with the following symptoms of lymphoedema? If you do not experience any of the symptoms, mark the "not applicable" box.

	Very little/ Little	Somewhat/ Moderately	Quite a lot/ Very much	
Swelling	☐	☐	☐	Not applicable ☐
Heaviness	☐	☐	☐	Not applicable ☐
Tightness	☐	☐	☐	Not applicable ☐
Aching	☐	☐	☐	Not applicable ☐
Tenderness	☐	☐	☐	Not applicable ☐
Stiffness	☐	☐	☐	Not applicable ☐
Weakness	☐	☐	☐	Not applicable ☐
Numbness	☐	☐	☐	Not applicable ☐
Tingling (pins & needles)	☐	☐	☐	Not applicable ☐
Pain	☐	☐	☐	Not applicable ☐
Range of movement	☐	☐	☐	Not applicable ☐

h If you did not complete the surgical treatment that was prescribed (if more than one procedure was involved), please indicate why not by ranking all that apply (eg. number 1 to 7) where 1 = the main reason:

No longer needed (treatment was effective)	☐	Did not improve symptoms	☐
Too expensive	☐	Stopped improving symptoms	☐
Too much effort	☐	Made symptoms worse	☐
Too time consuming	☐	Stopped due to side effects	☐

If there was another reason, please tell us here:

_____

_____

_____

_____

24a Have you used another type of treatment (not already listed) to treat your lymphoedema?

Yes ☐ No ☐ **Please go to Question 25**

b Who prescribed this treatment?

Physiotherapist ☐ Massage Therapist ☐ GP ☐

Self ☐ Other (please specify) ☐ _____

c In your own words, please tell us what this treatment entails (i.e., tell us what was prescribed, how often you attended sessions, how long each session was and the length of the total prescribed treatment period):

_____

_____

_____

d Were you able to complete this treatment as prescribed?

Yes, always ☐ Yes, sometimes ☐ Rarely ☐ Never ☐

e Are you currently using this treatment?

Yes ☐ No ☐

f How acceptable do/did you find the following aspects of this treatment as a treatment for lymphoedema?

Financial Cost:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Time required per session/day:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Duration of total prescribed treatment period (months/years/ongoing):

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

Level of discomfort during treatment:

☐	☐	☐	☐	☐
Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable

g Did this treatment help with the following symptoms of lymphoedema? If you do not experience any of the symptoms, mark the "not applicable" box.

	Very little/ Little	Somewhat/ Moderately	Quite a lot/ Very much	
Swelling	☐	☐	☐	Not applicable ☐
Heaviness	☐	☐	☐	Not applicable ☐
Tightness	☐	☐	☐	Not applicable ☐
Aching	☐	☐	☐	Not applicable ☐
Tenderness	☐	☐	☐	Not applicable ☐
Stiffness	☐	☐	☐	Not applicable ☐
Weakness	☐	☐	☐	Not applicable ☐
Numbness	☐	☐	☐	Not applicable ☐
Tingling (pins & needles)	☐	☐	☐	Not applicable ☐
Pain	☐	☐	☐	Not applicable ☐
Range of movement	☐	☐	☐	Not applicable ☐

h If you are not currently using this treatment, please indicate why not by ranking all that apply (eg. number 1 to 7) where 1 = the main reason:

No longer needed (treatment was effective)	☐	Did not improve symptoms	☐
Too expensive	☐	Stopped improving symptoms	☐
Too much effort	☐	Made symptoms worse	☐
Too time consuming	☐	Stopped due to side effects	☐

If there was another reason you are not currently using this treatment, please tell us here:

_____

_____

_____

_____

The following questions relate to your overall experience of lymphoedema treatments.

25 Do/did you need another person to assist you with doing the treatment that has been prescribed for your lymphoedema?

Yes, all the time ☐ Yes, sometimes ☐ No ☐

26 When you need assistance, do you have someone who is able to provide it?

Yes, all the time ☐ Yes, sometimes ☐ No ☐

27 How important is it to you that a particular treatment results in an improvement in the following symptoms in order for you to continue with that treatment?

Swelling	1 Not important at all	2 Not very important	3 Does not bother me	4 Important	5 Very important
Heaviness	1 Not important at all	2 Not very important	3 Does not bother me	4 Important	5 Very important
Tightness	1 Not important at all	2 Not very important	3 Does not bother me	4 Important	5 Very important
Aching	1 Not important at all	2 Not very important	3 Does not bother me	4 Important	5 Very important
Tenderness	1 Not important at all	2 Not very important	3 Does not bother me	4 Important	5 Very important
Stiffness	1 Not important at all	2 Not very important	3 Does not bother me	4 Important	5 Very important
Weakness	1 Not important at all	2 Not very important	3 Does not bother me	4 Important	5 Very important
Numbness	1 Not important at all	2 Not very important	3 Does not bother me	4 Important	5 Very important
Tingling	1 Not important at all	2 Not very important	3 Does not bother me	4 Important	5 Very important
Pain	1 Not important at all	2 Not very important	3 Does not bother me	4 Important	5 Very important
Range of movement	1 Not important at all	2 Not very important	3 Does not bother me	4 Important	5 Very important

28 In your own words, could you describe the level of change in your lymphoedema that you would need to see to consider a given form of treatment as being successful (e.g., "want to see a size reduction of more than 10%"; "just want a reduction in the severity of my pain", etc)

_____

_____

_____

29 Circle the response which most accurately reflects how important the following factors relating to lymphoedema status are to you.

Improvement in visual appearance

1	2	3	4	5
Not important at all	Not very important	Neutral	Quite important	Very important

Able to wear normal clothing

1	2	3	4	5
Not important at all	Not very important	Neutral	Quite important	Very important

Improvement in function

1	2	3	4	5
Not important at all	Not very important	Neutral	Quite important	Very important

Improvement in mobility

1	2	3	4	5
Not important at all	Not very important	Neutral	Quite important	Very important

Finally, a little about you:

30 Which ONE of the following best describes your **current** living arrangement?

- Living alone with no children ☐
- Single parent living with one or more children ☐
- Single and living with friends or relatives ☐
- Couple (married or defacto) living with no children ☐
- Couple (married or defacto) living with one or more children ☐
- Other *(please specify):* ☐ _____

31 Do you have private health insurance?

No	☐
Yes, hospital only	☐
Yes, extras only	☐
Yes, hospital + extras	☐

32 What is the **highest** educational qualification you have completed? *(Tick one only)*

Year 10 or less	☐	Associate or undergraduate diploma	☐
Year 11	☐	Bachelor degree	☐
Year 12	☐	Post-graduate diploma	☐
Trade or business certificate	☐	Masters degree or Doctorate	☐
Apprenticeship	☐	Other (*please specify*): _____	☐

33 Please add up the amount of **BEFORE-TAX** income received by **ALL** members of your household, and tick the box that comes closest to this number. Please indicate income either per year, per fortnight or per week.

Per year		**Per week**	
less than $15,600	☐	less than $300	☐
$15,600-20,799	☐	$300-399	☐
$20,800-25,999	☐	$400-499	☐
$26,000-31,199	☐	$500-599	☐
$31,200-36,399	☐	$600-699	☐
$36,400-41,599	☐	$700-799	☐
$41,600-51,999	☐	$800-999	☐
$52,000-72,799	☐	$1,000-1,399	☐
$72,800-93,599	☐	$1,400-1,799	☐
$93,600-$129,999	☐	$1,800-2,499	☐
$130,000 or more	☐	$2,500 or more	☐
Do not know	☐	I do not want to answer this question	☐

34 What is your height, without shoes on?

_____ cm

35 How much did you weigh:

When your lymphoedema was diagnosed? _____kg

When you were at your heaviest since diagnosis of your lymphoedema? _____kg

Now? _____kg

36 Please circle the number between 1 and 7 that best applies to you.

How would you rate your **overall health** during the past week?

1	2	3	4	5	6	7
Very Poor						Excellent

How would you rate your **overall quality of life** during the past week?

1	2	3	4	5	6	7
Very Poor						Excellent

37 Do you have anything else you would like to tell us about your lymphoedema and/or treatment you have used? Please do so here:

_____

_____

_____

_____

_____

_____

_____

Thank you for completing this questionnaire!

APPENDIX B

Participant responses providing additional information about lymphoedema and/or treatment

Exercise
Hydrotherapy - twice weekly, in a group specifically for lymphoedema patients helps incredibly with symptoms. Overcomes embarassment in wearing bathers because everyone there has swollen limbs. Good social event, lots of laughs!
I have been doing hydro for the past 2 or 3 years and found that this by far was the most successful treatment of my lymphoedema, but could always fall back on the garments when not being able to participate in hydro.
Support groups
Being part of a support group led by a qualified lymphoedema therapist makes a huge difference. Gives better understanding of the condition, advice available as required on a weekly basis and friendship and understanding from other people facing the same discomforts.
I go to a help group once a month it makes me feel good after as I know that I am not on my own.
Long time to diagnosis preventing early intervention
I wish I had been informed following surgery for breast cancer that I could get lymphoedema and what symptoms to be aware of. I could then have got treatment earlier and my arm might have been more reduced in size.
I wish I had had more information that you could get lymphoedema from surgery following removal of lymph nodes and that a massage be given following the operation.
The size of my left arm has never been less than when it was diagnosed by a physio approx. 2 years after surgery. Therefore early identification and treatment of lymphoedema are needed to prevent this initial swelling. Could NHMRC guidelines recommend arm measurements beofre breast surgery and at 6/12 intervals afterwards? Maybe BreastScreen could take these measurements prior to surgery. I think early detection and intervention could have helped me greatly to manage it successfully.
The worst part was taking so long to get diagnosed, and not knowing what the swelling was. I had 2 lots of clothes and shoes, one for when it was bad and another for when it was a bit better. I try to handle things myself now.
Accessing appropriate information
There doesn't appear to be much information about treatments. I hadn't heard of treatments mentioned in this survey.
Treatment and advice given was very haphazard, sometimes conflicting and confusing.
Since 2001, it has been extremely difficult to find out more about treatment options and professionals that can help me.
Cost
I have been hospitalised many times because of cellulitis in my lymphoedema.Being a pensioner, I would find it very helpful to receive some financial help to buy the garments I need to manage my lymphoedema. Presently I pay over $120 for each garment.
The cost of garments and treatment makes it very difficult to adequately manage my condition.
I would very much like to try the bandaging, but distance and cost do not make this possible. I also believe the Government should help with the cost of the compression sleeve. The hospital benefits return some, but still very expensive $285 twice a year.
Accessing health professionals (time, location and suitably qualified)
Finding a qualified private practitioner is very hard. Regular massage by physio or therapist is

vital - it may be possible to self massage with an arm only, but it is virtually impossible to self massage trunk and legs properly.
For me the biggest issue is time! I work full time and cannot undertake much of my work outside of standard business hours. Treaters need to understand that working less thatn F/T is not an option.
Have tried a number of lymphoedema physios and have found their treatment to be very varied. Some beneficial, others waste of time (and money). Matter of shopping around although not many to choose from.
Living in a rural area, there is no real treatment choice. It is not possible to have complex physical therapy as there is not the staff or the room to carry it out. Our nearest clinic is over 3 hours drive away. Education re self massage and exercises is barely adequate at our public facilities and most lymphoedema clients have to work out their own treatments.
I have found some practioners to be more helpful than others, which I suppose is normal in most areas of life. Some were basically not interested or I consider to be incompetent.
Experiences with health professionals
I would especially like leaders in the lymphoedema industry such as Neil Piller stop using abusive, derogatory and demeaning language to describe us and our body parts. My lymph system is NOT lazy, sluggish or broken down - not AM I! My limbs are not swampy, teeming of bacteria or backed up. Nor am I with language like that its no wonder a majority of us are depressed!
Medical professionals (oncologists/breast surgeons) fail or underestimate the effects of lymphoedema - this risk was never mentioned pre-surgery/after diagnosis nor suitable treatment offered.
It would be nice to get a bit more understanding from the medical professionals. Because we conceal our unglamourous legs and hopefully don't complain too much as we try to live an active life, doesn't mean we don't suffer, especially in the hot weather.
Weather
My lymphoedema is totally controlled by daily wearing of a compression stocking. It is a much more difficult condition to live with in summer due to the heat. The garments are hot and harder to hide in a skirt/dress than in trousers in winter.
My feet and ankles swell in hot/warm weather. Generally speaking, the hotter the weather, the worse the swelling.
Stress, anxiety, distress, frustration
I am also very bitter about the reality that since my first child was born (1992) I have had limited opportunities to share in family experiences due to my lymphoedema. It is on my mind 24/7 - TRUE!
To go through cancer and end up having lymphoedema was, to say the least, very upsetting.
Being diagnosed with lymphoedema was probably worse than my cancer diagnosis! Cancer can often be cured, but you can never forget you had it with lymphoedema,
I feel anxious that the condition will worsen.
In the early days of diagnosis I was depressed upset and angry that it changed and affected my life - young children, working on the farm in cattle yards was out and treatment was too hard to access.
Focus on breast cancer
Overall, a greater awareness of lymphoedema in medical circles, and most emphasis seems to be on post breast ops - how about us 'legs'?

Selfishly, those of us with leg problems (let alone more esoteric cases) get tired of the major stress on arm treatments. At least they don't have to stand and walk on arm.
I would like to see primary lymphoedema researched as thoroughly and passionately as breast cancer-related lymphoedema, and for people of primary lymphoedema to be no longer 'blamed' for their condition or treatment as an inferior class of lymphoedema citizen.
My lymphoedema is related to melanoma not breast cancer. Most assistance programs are aimed at the breast cancer survivor and my isolation after diagnosis was debilitating in itself.
Public awareness
I would just like the general public to understand what lymphoedema really is. Also more medical people.
I would like people made more aware of lymphoedema, especially GPs.
More information should be available to educate the general public about possibilities available to relieve their discomfort.

APPENDIX C

Letter to participants and validity questions

Queensland University of Technology

improving health outcomes for people

Dear LAQ members,

Last year you may have been contacted by researchers at the Queensland University of Technology and invited to participate in a study of the factors which motivate and prevent people from adhering to treatment for lymphoedema. The information collected will be used to inform future management of lymphoedema, so that it takes into better account the key concerns for those living with lymphoedema.

The second stage of this project involves checking whether the questionnaire used for this study collects information about ***all*** relevant factors that influence decisions regarding treatment for lymphoedema. If you choose to participate in this project, please read through the Participant Information Sheet and instructions at the beginning of the questionnaire.

Your participation is voluntary, we ask for no identifying information and returning the questionnaire implies you are consenting to participate.

Thank you for your ongoing support in our research endeavours.

Anna Finnane
PhD Student
School of Public Health
Queensland University of Technology
a.finnane@student.qut.edu.au
(07) 3138 5817 / 0438 722 547

The issues faced in the treatment and management of lymphoedema

Validity and Reliability of the Questionnaire

About the Questionnaire

For the questions about different treatment types (starting on Page 5):

1. Was there any aspect of the ***acceptability*** of lymphoedema treatment that has impacted on you and was not addressed on the questionnaire? (ie. apart from cost, time, duration and discomfort)

_____
_____
_____

2. Have you had **physical symptoms** of lymphoedema that were not listed on the questionnaire? If so, what were they?

_____
_____

"Question 29. Circle the response which most accurately reflects how important the following factors relating to lymphoedema status are to you"

3. Are there any **other factors that are important** to you in terms of treatment effectiveness, that were not listed? (ie. apart from improvement in visual appearance, ability to wear normal clothing, improvement in function and mobility)

_____
_____
_____

APPENDIX D

Follow-up reminder postcard

A friendly reminder

Hi,

Around two weeks ago you would have received a survey from us in the mail.

Thankyou to all those who have already completed and returned it, we appreciate your time and participation.

To those who have not yet completed the survey, we would be very grateful if you could take the time to do so - your information is important to us. If you have not received a survey or have misplaced it, please call me on (07) 3138 5677.

Regards,

For more information, please contact Anna Finnane (07) 3138 5677 or a.finnane@student.qut.edu.au

APPENDIX E

Participants' treatment descriptions

Met criteria	Did not meet criteria
Complex Physical Therapy	
MLD daily (for approx 1 hour) for 2 weeks, followed by application of compression bandaging. Self exercise 1-2 times p/day. Skin care is a daily ritual for me.	Compression bandaging x2 6 months apart. Now wear a support sleeve. Massage every 6-12 months.
Manual lymph drainage – weekly, 30 mins. Compression bandaging – fortnightly. Total period – 6 weeks.	Manual lymph massage weekly for 6 weeks by physiotherapist followed by 6 monthly visits.
3 times a week, one hour sessions for 4 months, massage and compression bandaging.	Body flow machine (my own) daily 20 mins. Two days of hydrotherapy 1 hour.
Manual Lymphatic Drainage	
Clearance of lymph nodes, manual drainage of lymph fluid – arm, hand and breast area – right hand side – also other areas of body e.g., legs, trunk, stomach, left arm – by trained massage therapist. Began treatments in 2009. Sessions are monthly, last approx 1 hr each and are ongoing indefinitely.	Exercises for arm mobility and general good health. To massage from arm across the chest. Self-treated.
Treated by 2 people, one every 2 weeks. Physio – light drainage and organises compression garment – 20 minutes. Lymphatic trained masseur – 1 hour – solid massage, most beneficial.	Stretching and stroking exercises after attending classes suggested by hospital physio.
Massage by physio – 3 monthly, 30 mins each session, 5 years.	Given crystals to try in evening, could not keep them in place.
Self-administered massage	
Gentle massage under axilla over shoulders across chest, deep breathing. Gentle sweeping strokes 5-10 mins most days, ongoing.	Just initial 6 weeks – massage followed by pressure bandaging approx 1 hr/day
Activating drainage points and lightly massage stroking towards poi nt. Draining strokes etc. time approx 15 minutes.	Massage, bandaging, exercise
I was shown by physio to do at home.	The exercises take approx 20 minutes.
Laser Therapy	
Every 4 to 5 weeks lying on a table having both overhead and hand held laser. Mainly for fibrosis which causes restriction/pain etc which blocks and causes lymphoedema.	Started with Body Flow, found it helped.
Laser beam applied to affected limb. Session was for 20-30 mins daily for 1 month.	
Spot laser is occasionally used depending on the state of my arm at each massage session.	

Pneumatic compression pumps	
I purchased a pump at great expense in 2000 when lymphoedema first diagnosed. It is a noisy box that blows air into a plastic leg sheath an squeezes the leg then releases the air and builds up the air pressure again etc.	I used a body flow machine 5 times a week. It helps to keep the limb soft but does not decrease the circumference.
Purchased my own pump and use it twice a day for 1 hour.	Suction cups are placed on the limb in certain points and it generates a vibration and suction for about 10 minutes every month.
Was able to use pump at home for 2 weeks. Applied each night for 1 hour.	I go to the Mercy Lymphoedema Clinic every 6 months to measure and have new compression stocking.
Compression bandaging	
Start with measurement of arms and fingers. Different grades of pressure to ends area of fingers and arm up to shoulder. This is done over 6 weeks every day until measurements plateau then measured for compression glove and sleeve.	The physiotherapist recommended I wear a compression bandage and stockings. I only had one session for 1 hour.
1 month, x3 daily, 2 layers of soft bandages and 1 outer stretchy firmer bandage.	Compression sleeve on long air flights.
Changing bandages every couple of days and seeing therapist 1 to 2 weeks.	To help with pain and swelling.
Compression garments	
Waist high tights, both legs compression 20-30mmHg. Worn continually when not in bed, daily use.	Massaging, then shower, then full compression bandaging. This was initially done once a week for a month, very rarely now but stronger bandaging 3 times a week.
Arm and hand compression garments. Nearly always wear them except in hot weather. Leg too uncomfortable to wear. Have worn garment on and off for 6 years.	The bandaging was very painful and used 4 days every few months.
Compression stocking which I use regularly.	Just do it.
Prescribed exercises	
Most days for 3-5 minutes, 3-4 times a day, left arm stretches, rotation, pressure against wall. Still do exercises prescribed in 2001.	Gentle massage of lymph system.
Exercises from education session at Mercy Lymphoedema Clinic. Generally incorporated throughout the day e.g., when sitting – moving feet in heel-toe action, e.g., like walking, sitting down, standing at regular intervals, standing up on balls of feet.	Physiotherapist was trained to manage lymphoedema. 1 hour sessions weekly. I now have massage fortnightly.
Range of exercises to improve lymphatic drainage twice a day for approx 10 mins ongoing.	There was no long session, part of check up.

Surgery	
Venous anastomosis for right (unsuccessfully as lymphoedema present for 14+ years and lymph vessels withered). Left arm successful and does not require compression garment.	Lumpectomy and revision lumpectomy, sentinel node biopsy
Liposuction to right arm followed by 10 days of compression bandaging and compression garments.	
Debulking of scrotal area. Plastic surgeon removed fibrous tissue. Only bottom of scrotal area was operated on removing approx 1.6kg of tissue. Second operation is required to reduce tissue on top half of scrotal area.	

APPENDIX F

Results: Acceptability of cost, time, duration and discomfort for all treatments

Appendix F1

Proportions of participants reporting the acceptability of the financial cost of lymphoedema treatment

Treatment	Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable	Missing
Complex physical therapy	26 (14.8%)	33 (18.8%)	28 (15.9%)	33 (18.8%)	38 (21.6%)	18 (10.2)
Manual lymphatic drainage	36 (12.6)	64 (22.5)	33 (11.6)	71 (24.9)	47 (16.5)	34 (11.9)
Self administered massage	4 (1.2)	11 (3.3)	60 (18.1)	33 (9.9)	150 (45.2)	74 (22.3)
Laser therapy	9 (11.7)	12 (15.6)	19 (24.7)	11 (14.3)	20 (26.0)	6 (7.8)
Pneumatic pumps	3 (5.9)	5 (9.8)	12 (23.5)	8 (15.7)	11 (21.6)	12 (23.5)
Compression bandaging	24 (12.7)	33 (17.5)	35 (18.5)	35 (18.5)	33 (17.5)	29 (15.3)
Compression garments	92 (25.4)	98 (27.1)	32 (8.8)	75 (20.7)	48 (13.3)	17 (4.7)
Prescribed exercises	3 (1.0)	12 (4.1)	62 (21.2)	38 (13.0)	126 (43.2)	51 (17.5)
Surgery	2 (14.3)	5 (35.7)	2 (14.3)	3 (21.4)	0 (0.0)	2 (14.3)

Appendix F2

Proportions of participants reporting the acceptability of the time required per session of lymphoedema treatment

Treatment	Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable	Missing
Complex physical therapy	11 (6.3%)	24 (13.6%)	23 (13.1%)	49 (27.8%)	50 (28.4%)	19 (10.8)
Manual lymphatic drainage	6 (2.1)	29 (10.2)	42 (14.7)	89 (31.2)	88 (30.9)	31 (10.9)
Self administered massage	18 (5.4)	38 (11.4)	46 (13.9)	82 (24.7)	91 (27.4)	57 (17.2)
Laser therapy	3 (3.9)	6 (7.8)	18 (23.4)	22 (28.6)	23 (29.9)	5 (6.5)
Pneumatic pumps	1 (2.0)	10 (19.6)	8 (15.7)	15 (29.4)	7 (13.7)	10 (19.6)
Compression bandaging	22 (11.6)	29 (15.3)	35 (18.5)	43 (22.8)	27 (14.3)	33 (17.5)
Compression garments	17 (4.7)	42 (11.6)	74 (20.4)	72 (19.9)	105 (29.0)	52 (14.4)
Prescribed exercises	9 (3.1)	37 (12.7)	52 (17.8)	77 (26.4)	80 (27.4)	37 (12.7)
Surgery	1 (25.0)	0 (0.0)	1 (25.0)	0 (0.0)	1 (25.0)	1 (25.0)

Appendix F3

Proportions of participants reporting the acceptability of the duration of the treatment period

Treatment	Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable	Missing
Complex physical therapy	10 (10.3%)	11 (11.3%)	18 (18.6%)	20 (20.6%)	25 (25.8%)	13 (13.4)
Manual lymphatic drainage	15 (8.2)	17 (9.9)	34 (18.7)	41 (22.5)	48 (26.4)	26 (14.3)
Self administered massage	13 (5.9)	18 (8.2)	45 (20.5)	45 (20.5)	54 (24.7)	44 (20.1)
Laser therapy	1 (3.1)	6 (18.8)	6 (18.8)	9 (28.1)	7 (21.9)	3 (9.4)
Pneumatic pumps	1 (6.7)	0 (0.0)	3 (20.0)	4 (26.7)	1 (6.7)	6 (40.0)
Compression bandaging	13 (12.6)	11 (10.7)	21 (20.4)	23 (22.3)	17 (16.5)	18 (17.5)
Compression garments	22 (9.3)	31 (13.1)	44 (18.6)	41 (17.3)	60 (25.3)	39 (16.5)
Prescribed exercises	8 (4.0)	17 (8.6)	36 (18.2)	40 (20.2)	59 (29.8)	38 (19.2)
Surgery	2 (20.0)	1 (10.0)	1 (10.0)	5 (50.0)	1 (10.0)	0 (0.0)

Appendix F4

Proportions of participants reporting the acceptability of the discomfort of lymphoedema treatment

Treatment	Unacceptable	Somewhat unacceptable	Neutral	Somewhat acceptable	Very acceptable	Missing
Complex physical therapy	11 (6.3%)	27 (15.3%)	28 (15.9%)	38 (21.6%)	57 (32.4%)	15 (8.5)
Manual lymphatic drainage	5 (1.8)	6 (2.1)	43 (15.1)	61 (21.5)	146 (51.4)	23 (8.1)
Self administered massage	6 (1.8)	10 (3.0)	70 (21.1)	56 (16.9)	144 (43.4)	46 (13.9)
Laser therapy	1 (1.3)	3 (3.9)	10 (13.0)	10 (13.0)	47 (61.0)	6 (7.8)
Pneumatic pumps	2 (3.9)	3 (5.9)	15 (29.4)	11 (21.6)	10 (19.6)	10 (19.6)
Compression bandaging	26 (13.8)	41 (21.7)	31 (16.4)	36 (19.0)	28 (14.8)	27 (14.3)
Compression garments	28 (7.7)	78 (21.5)	53 (14.6)	86 (23.8)	80 (22.1)	37 (10.2)
Prescribed exercises	3 (1.0)	17 (5.8)	65 (22.3)	64 (21.9)	102 (34.9)	41 (14.0)
Surgery	3 (21.4)	5 (35.7)	1 (7.1)	5 (35.7)	0 (0.0)	0 (0.0)

APPENDIX G

Participants' reasons for discontinuing use of treatment

Reasons for discontinued use of treatment
Complex Physical Therapy
As a country resident (150km from Melbourne) access is restricted. Local hospital physio has been trained but does not have time for CPT.
It is no longer available at RPA. My massage therapist cannot afford the time, and I could not afford to pay her.
The time per day and total period of duration are fine, but working full time, it's hard to take the time off work to do it! The benefits for me were amazing!! Assistance with daily living and getting to and from appointments is also a barrier. (If I can't drive, how do I get there? Public transport in full bandages = not so easy)
Manual Lymphatic Drainage
Cannot afford to keep taking too much time off work. Most practitioners only work within standard business hours.
My therapist retired and I have been unable to locate a suitable replacement. I have tried a few and find the level of training and ability varies greatly.
I have not been able to find another physio offering this service - plenty of people who think they know - really shonky, and very worrying!
Self-administered massage
Difficult to massage back and chest well
Due to age I am finding it hard to do now, looking for a therapist in this area. Finding it hard to stretch to do the strokes up and down the leg
My husband did complete the 1 month as directed but found it very hard and time consuming to continue with the lymphoedema 'milking' process of my legs. It was very effective though. Trying to do it myself seemed ineffective.
Laser Therapy
Laser therapy is not available in all states. Distance to travel is too far.
Physio at hospital do not have time to do it - too expensive at private practice.
Distance to therapist - however certainly improved fibrotic areas.
Pneumatic compression pumps
No longer available to me.
Not recommended by everyone, can make condition worse evidentally.
Told not to use outside of complex physical therapy, which I only had for 10 sessions in 1 month. Would like to have more.
Compression bandaging
Definitely too time consuming and a lot of effort involved with putting bandage on, taking it off, washing them all and rolling the 12 individual rolls up to use again. Of all the treatments I've tried this is the worst
Too hard to work in full bandages. I drive for work, cannot drive in full bandages. Finding pants and shoes to fit very difficult.
It's very hard to do - to know whether you are doing it right or not. It needs to be done by a professional.
Compression garments
Found them very uncomfortable they ride down and then dig in under the knee causing pain.
Have just received compression garment for left leg and that is help considerably with my leg. Arm only - compression garment for arm/hand is too inhibiting to use as it cuts off circulation to tips of fingers despite exhaustive attempts to rectify by manufacturer. I have back and left shoulder injury which

makes it impossible to put on garments. I live alone.
Stockings too difficult to get on/off for minimal improvement. Wear them when flying more than 4 hours.
Prescribed exercises
Lack of time. Am my husband's carer and this year I have been busy but intend restarting exercises and massage very soon.
To make a worthwhile improvement in me I think I would have to do the exercises morning noon and night and I still may not improve. I have tried upon occasion to really do them to no great avail.
At the age of 82 and having a range of health issues I no longer have the energy to do exercises. Osteoarthritis in knees, hips, arms, shoulders, hands, neck, feet.

APPENDIX H

Results: Bivariate effect modification tables

Table 1 Bivariate associations between independent variables and use of compression garments, stratified by lymphoedema location

	All locations pooled		**Upper**		**Lower**		**Full body/Other**	
	n(%)	p-value	n(%)	p-value	n(%)	p-value	n(%)	p-value
Total participants	**362 (86.0)**		**182 (84.3)**		**163 (88.6)**		***17 (81.0)***	
Age								
Under 55 years	55 (88.7)		21 (84.0%)		29 (90.6)		*5 (100.0)*	
55-64 years	107 (87.7)		62 (89.9%)		38 (86.4)		*7 (77.8)*	
65-74 years	130 (87.2)		73 (85.9%)		54 (91.5)		*3 (60.0)*	
75 and over/missing	70 (79.5)		26 (70.3%)		42 (85.7)		*2 (100.0)*	
		.556		0.165		0.918		0.140
Household income								
<$20 799	57 (82.6)		26 (76.5)		28 (90.3)		*3 (75.0)*	
$20 800 – 36 399	57 (93.4)		30 (90.9)		23 (95.8)		*4 (100.0)*	
$36 400 – 51 999	49 (89.1)		24 (85.7)		21 (91.3)		*4 (100.0)*	
$52 000+	78 (90.7)		45 (91.8)		30 (90.9)		*3 (75.0)*	
Not known/not answering/Missing	121 (80.7)		57 (79.2)		61 (83.6)		*3 (60.0)*	
		.185		0.270		0.809		0.634

Categories with under 20 cases are italicised; effect modification was not considered.

Table 2 Bivariate associations between independent variables and use of self-massage, stratified by lymphoedema location

	All locations pooled		**Upper**		**Lower**		**Full body/Other**	
	n(%)	p-value	n(%)	p-value	n(%)	p-value	n(%)	p-value
Total participants	**332 (78.9)**		**179 (82.9)**		**135 (73.4)**		***18 (85.7)***	
Private Health Insurance								
No/DVA card/Missing	66 (68.8)		30 (76.9)		29 (59.2)		*7 (87.5)*	
Yes	266 (81.8)		149 (84.2)		106 (78.5)		*11 (84.6)*	
		.018		.024		.017		.854

Categories with under 20 cases are italicised; effect modification was not considered.

Table 3 Bivariate associations between independent variables and use of manual lymph drainage, stratified by lymphoedema location

	All locations pooled		**Upper**		**Lower**		**Full body/Other**	
	n(%)	p-value	n(%)	p-value	n(%)	p-value	n(%)	p-value
Total participants	286 (67.9)		162 (75.0)		107 (58.2)		17 (81.0)	
Age								
Under 55 years	45 (72.6)		20 (80.0)		21 (65.6)		*4 (80.0)*	
55-64 years	88 (72.1)		48 (69.6)		31 (70.5)		*9 (100.0)*	
65-74 years	101 (67.8)		64 (75.3)		35 (59.3)		*2 (40.0)*	
75 and over/missing	52 (59.1)		30 (81.1)		20 (40.8)		*2 (100.0)*	
		.390		.788		.127		.119
Private Health Ins								
No/DVA card/Missing	55 (57.3)		29 (74.4)		20 (40.8)		*6 (75.0)*	
Yes	231 (71.1)		133 (75.1)		87 (64.4)		*11 (84.6)*	
		.034		.814		.007		.862

Categories with under 20 cases are italicised; effect modification was not considered.

Table 4 Bivariate associations between independent variables and use of compression bandaging stratified by lymphoedema location

	All locations pooled		**Upper**		**Lower**		**Full body/Other**	
Total participants	188 (44.7)		89 (41.2)		89 (48.4)		10 (47.6)	
Age	n(%)	p-value	n(%)	p-value	n(%)	p-value	n(%)	p-value
Under 55 years	32 (51.6)		*11 (44.0)*		*18 (56.3)*		*3 (60.0)*	
55-64 years	57 (46.7)		27 (39.1)		26 (59.1)		*4 (44.4)*	
65-74 years	62 (41.6)		34 (40.0)		26 (44.1)		*2 (40.0)*	
75 and over/missing	37 (42.0)		*17 (45.9)*		*19 (38.8)*		*1 (50.0)*	
	CS	.593	NS	.981	CS	.251		.719

Categories with under 20 cases are italicised; effect modification was not considered.